

**T H E** National Association of Criminal Defense Lawyers

# CHAMPION

November 2010

## The Criminalization of End-of-Life Care

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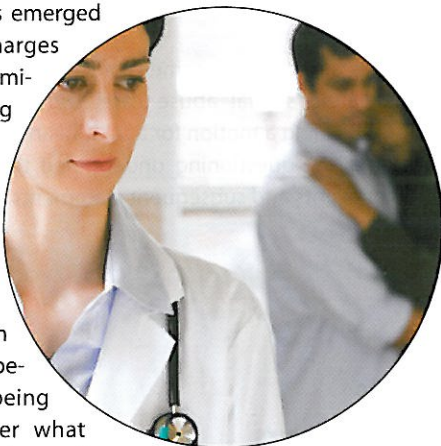


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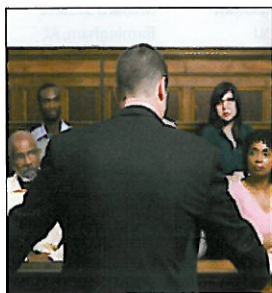
A disturbing trend has emerged involving criminal charges being levied against family caregivers treating end-of-life elders with dementia. Noncaregiver relatives and representatives of state or federal agencies are turning to the criminal justice system for redress when they believe an elder is being abused or died under what they consider suspicious circumstances. In some cases, lay caregivers have faced allegations of homicide. These cases focus on the care received by the decedent, and thus the defense attorney must retain the services of a geriatric specialist or palliative care physician.



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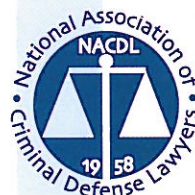
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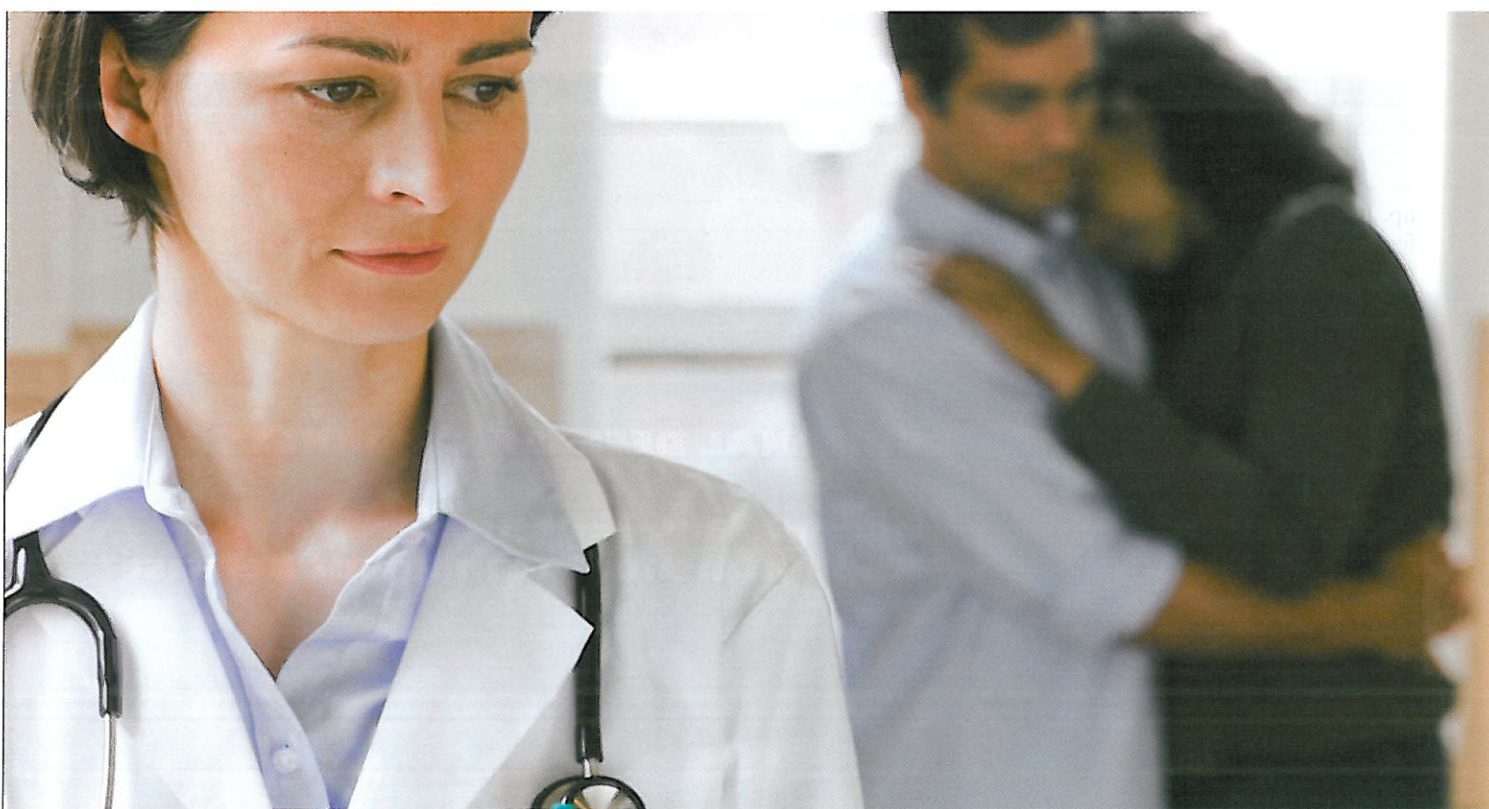
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## NACDL MISSION

Ensure justice and due process  
 for persons accused of crime.  
 Foster the integrity, independence and  
 expertise of the criminal defense profession.  
 Promote the proper and fair  
 administration of criminal justice.







## The Criminalization of End-of-Life Care and the Emergence of 'Clinical Forensic Medicine'

A disturbing trend has emerged involving criminal charges being levied against family caregivers treating end-of-life (EOL) elders with dementia. In the most common scenario, a younger family member (often the eldest daughter) becomes the home caregiver to an elderly relative as a result of one or more factors: (1) the family has been informed that further hospitalization will not be provided because there is simply nothing more medically that can be done for this patient in a hospital setting; (2) the family does not have the monetary resources to provide any care beyond what they can provide at home; (3) the family desires to honor the elder's wish to die at home without invasive hospital-based diagnostics, treatments, or advanced technology being utilized during the EOL phase; or (4) the family unit or the healthcare provider is not aware of the rights of the patient and the obligations of the treating health-

care provider surrounding proper certification under the Medicare Hospice Benefit during the EOL phase.

It is important to note the insufficiency of resources needed to train and monitor lay caregivers outside of a certified home hospice clinical scenario. Moreover, there are no guidelines for providing lay care, and no programs to educate families about when they may need assistance or guidance. To compound matters further, unrecognized caregivers could easily burnout and therefore may complicate the delivery of care, which ultimately will interfere with the health and welfare of all parties involved. Pilot programs are being considered to provide counseling and on-site training to address these problems.

### Elder Abuse Prosecutions

In addition to the other problems mentioned, the criminal justice system is now involved. Noncaregiver relatives and representatives of local, state, or federal agencies are now turning to the criminal justice system for redress when they believe an elder is being abused or died under what they consider suspicious circumstances. In some cases, lay caregivers who believed they were honoring their loved one's wishes to stay at home at the end of life have faced allegations of homicide.

Why is this of importance and concern to the criminal defense bar? The American Geriatric Society (AGS) literature points out that the fastest growing population demographic in the country is the over-85 age group. It is widely reported that the majority of these patients have an element of dementia (including mild cognitive impairment) and up to 30 percent of these patients have the commonest form of dementia: Alzheimer's disease.<sup>1</sup> Often undiagnosed in the hands of an inexperienced cli-

BY JAMES FARRAGHER CAMPBELL AND JOHN H. FULLERTON

nician during the early stages, today the diagnoses of various forms of dementia may often be reliably determined clinically, particularly if neuro-psychological testing is also utilized during the work-up. It is therefore not necessary to wait for a post-mortem analysis as previously widely believed.

The genesis of "elder abuse" prosecutions can be traced to the many state and federal regulations now imposed on nursing homes that were meant to eliminate much of the widespread gross negligence and elder abuse (including the "warehousing of elders" in some nursing homes) occurring when patients 85 years and older needed long-term care. The detection of these situations may have encouraged some plaintiff's lawyers to pursue cases where fees and augmented damages could be awarded to the estate. These laws were drafted to attract attorneys to take these kinds of cases; previously, more limited damage awards and recoveries had impeded prosecutions. With increasing frequency, these same nursing homes, which are now under much stricter regulatory oversight, find themselves filled with these patients over 85 years of age who have co-existent dementia plus frailty.

When a family member suspects an elder has been neglected or abused in these facilities, these new statutory regulations buttress their civil claims for relief. But now, in certain instances, plaintiffs have also turned to the criminal justice system because of the enhanced investigatory resources it provides, as well as the leverage such criminal charges provide the plaintiffs in the civil cases. Consequently, there have been instances where caregivers in these facilities have been charged with homicide. These events have opened the door to the prosecution of lay caregivers, and to some extent their professional counterparts ministering to family members at home.

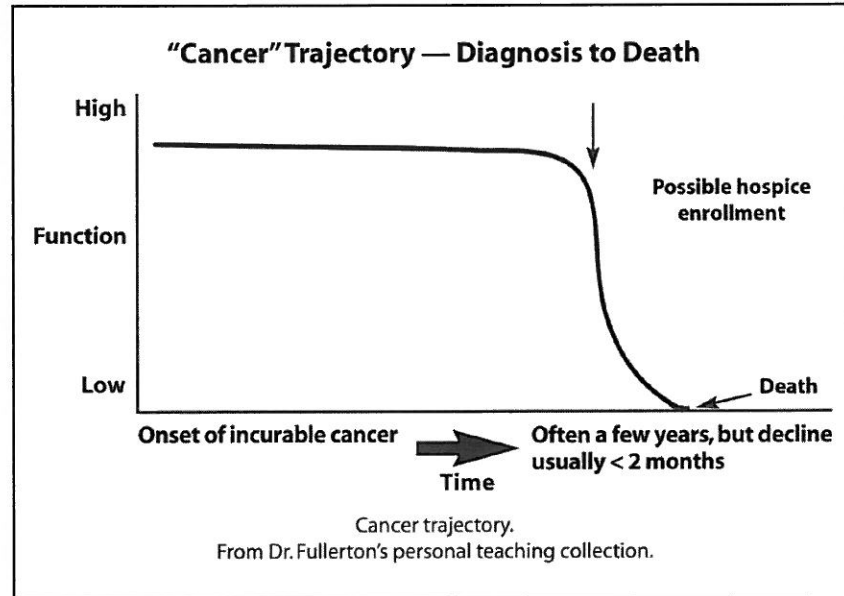
## Lack of Expertise And Training

The problems inherent in civil cases with regard to expert witnesses carry over to the criminal prosecutions, except the impact of the "experts" generally only enhances the possibility of the improper filing of criminal charges. This flows from police or prosecutor reliance upon the opinion of medical examiners, forensic pathologists, and some forensic psychiatrists who simply do not have expertise in this specific area. While these individuals may have medical

## Illness Trajectories

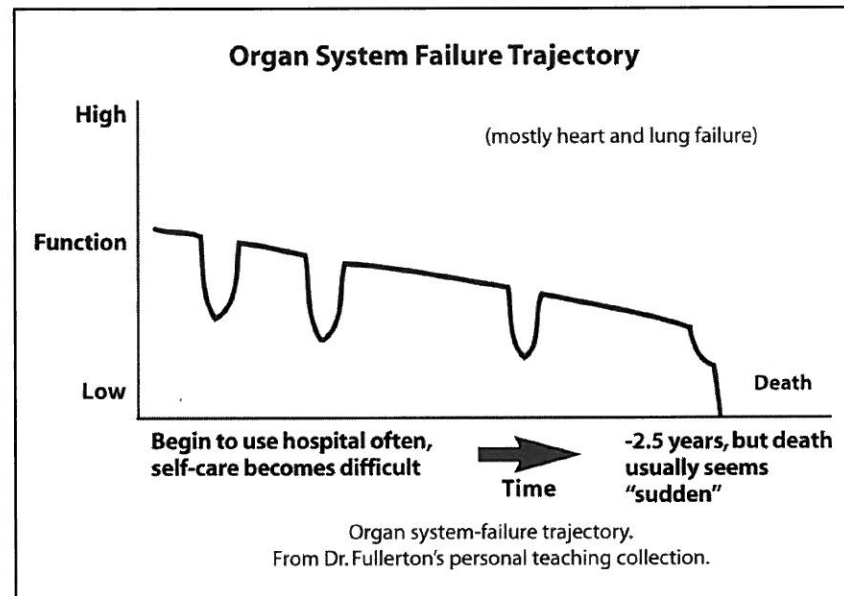
Patients with advanced illness can be categorized broadly by the clinical course of their disease process. This concept of chronic-illness trajectories can be helpful in estimating prognosis, revisiting goals of care and anticipating the patient's physical/psychological/social/spiritual needs. Three distinct illness trajectories have been described for patients with chronic, progressive illness: cancer, organ failure and dementia trajectories.<sup>[4]</sup>

Figure 1



**Cancer trajectory:** Patients have a slow, gradual decline for prolonged periods, followed by a short period of rapid decline, which leads to death.

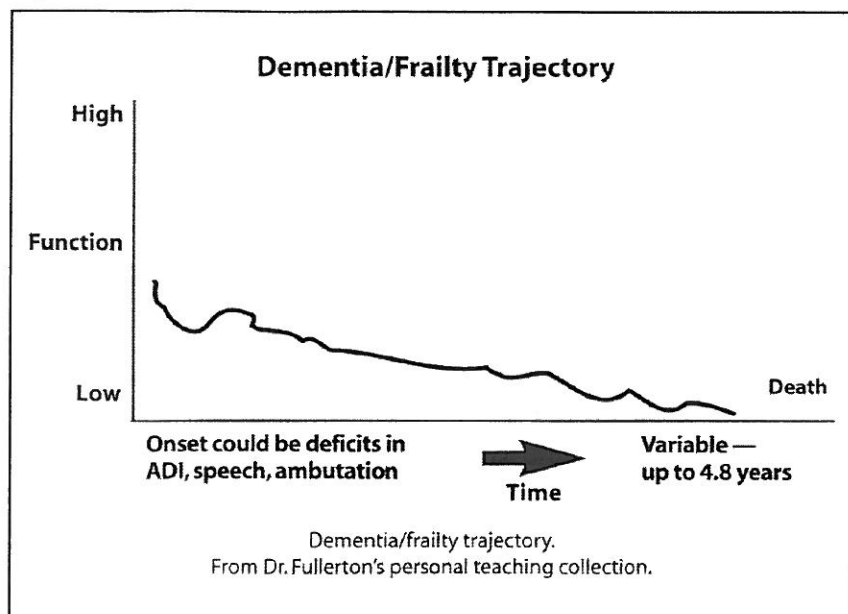
Figure 2



**Organ failure trajectory (i.e., congestive heart failure, chronic obstructive pulmonary disease):** Patients have a slow, gradual decline with periods of acute exacerbations and rapid deterioration from which they have a partial recovery. The exacerbations become more frequent and severe with time, with any one of these exacerbations placing the patient at high risk of death. Eventually, one of the exacerbations leads to death, which may then seem to be more of a sudden event as the timing of death is less clear.



Figure 3



**Dementia trajectory:** Patients have a slow, progressive decline with small ups-and-downs of physical and cognitive function. Frequently, death follows a secondary illness, such as pneumonia.

knowledge, and at times “chutazpah,” they lack the clinical training and experience necessary to accurately evaluate not only capacity issues, but also determine the cause of injury or death in elder end-of-life care cases. In fact, pathologist Vincent Demaio, a pioneer in the field of forensic pathology, recently stated that they are currently “only at the frontier stage of assisting in these determinations of end-of-life dementia care cases,” and that “the chapter [to help the courts out] has simply not been written” by their discipline.<sup>7</sup>

Compounding matters further, these same forensic pathologists whom prosecutors have traditionally relied upon for evidentiary guidance in homicide trials do not have the clinical training and clinical experience to understand the body of evidence that a “clinical forensic medical” practitioner has. A defense attorney in these cases must retain a qualified, nationally certified, geriatric specialist with experience as a certified medical director of long-term care, a certified hospice medical director, or a palliative care physician. Ideally, a nurse specialist, a home care physician, and a nurse would be available too. Within this body of clinical training and experience, this new breed of clinically minded end-of-life care specialist has the knowledge that senile dementia-Alzheimer type (SDAT) is a diagnosis that routinely can be made clinically while the patient is alive and that the

limited life expectancy of these frail patients can be predicted. In contradistinction to the traditional forensic pathology teaching and testimony in courts, these patients routinely die directly from their underlying Alzheimer-type dementia. In fact, according to the American Academy of Hospice and Palliative Medicine (AAHPM) “trajectories of disease” for SDAT, frailty may be “plotted out” to depict the timing and the common final pathway of the demise of these end-stage, frail patients. (See Figures 1-3.)<sup>8</sup>

Many medical examiners and forensic criminal pathologists who routinely testify in court have acknowledged that they have very little experience with the kinds of autopsies or forensic analysis present in elder abuse or elder death cases. One reason for this is because the remains of most elders who expire at home, while under the care of a primary medical doctor of record, are generally transported directly to a mortuary following hospice and palliative care. The coroner rarely receives notification, and it is rare for an autopsy to be required or requested. Therefore, these types of traditional examiners are not present while the patient is alive during this EOL phase — when the accumulating “clinical forensic evidence” may be viewed and chronicled by allied qualified EOL clinical practitioners. Furthermore, the delin-

real-time is therefore directly relevant and most correlated with the circumstances surrounding the most accurate characterization of the incident death.

Forensic analyses in these cases differ greatly from those found in other criminal cases. Consequently, the “experts” involved will be different. They will require knowledge, training, experience, and board certification in the areas of geriatrics (ABIM), hospice and palliative medicine (ABHPM), long-term medical directorship (CMD), and nursing. Consequently, this new breed of “clinical forensic medical experts” will be required to more accurately assess these specialized EOL care cases for the courts.

Pilot programs may also be developed by adding “clinical forensic medical” tracts within the curricula of pre-existing gero-psychiatry, general psychiatry, geriatric, and palliative fellowship training programs; additionally, this forensic tract may likewise be added toward advancement in the certification process of Long-Term Care Medical Directors (CMD), Hospice Medical Directors (CHMD), Home Care Certified physicians by the AAHCP, and forensic palliative care training of hospice and palliative care nurses.

The early underpinnings of the science of “clinical forensic medicine” can be traced to the criminal justice system in Great Britain almost 50 years ago. In the United States, however, the judicial climate has remained mostly mute and dormant. Until the 1990s, U.S. courts failed to recognize, or at times require, the forensic utility of this established and growing body of clinical forensic science. More recently, with the rapid accumulation of clinical evidence surrounding this new specialty in the United States, the need has now been recognized, and this clinical evidence is now available for American courts.

## Hypotheticals

The necessity of enlisting specialized experts with qualifications and clinical hands-on experience in EOL cases (as clinical forensic medical experts) is demonstrated by a couple of hypothetical situations.

Consider a situation in which a relative who does not participate in the caregiving believes the elder patient is being intentionally starved and dehydrated. Imagine that this individual, well-intentioned though she may be, prevails upon the police or district attorney to investigate the case and file criminal charges.

The lab results from the medical examiner or pathologist reveal evidence of Protein-Calorie Malnutrition, Cachexia (wasting) and profound dehydration with the associated evidence of severe pre-renal azotemia (kidney failure from severe dehydration and "volume contraction"), hyperkalemia (critically elevated serum potassium levels), severe hyponatremia (critically elevated serum sodium levels), and various forms of metabolic acidosis, hypoalbuminemia (low serum proteins), anemia of chronic disease and lymphopenia (depressed white blood cell counts). To the medical examiner or pathologist without specialized training, these results may indicate evidence of elder abuse.

However, specialty literature in the hospice and palliative medicine domain clearly outlines the trajectory of chronic diseases. (See Figures 1-3.) For example, it is common knowledge within the AAHPM that patients really do expire of end-stage Alzheimer's disease.<sup>4</sup> It is not necessarily an associated or unassociated co-morbidity (as with Myocardial Infarctions, Pulmonary Embolisms, Cerebral Vascular Accidents, or GI Bleeding), or sepsis (from blood poisoning, terminal wounds, or a urinary tract source), but, in fact, according to the CDC in 2004 age-adjusted mortality data, Alzheimer's disease was the seventh leading cause of death.<sup>5</sup>

Further, the weight of the hospice and palliative medicine literature currently supports the approach that artificial hydration and artificial nutrition neither prolong life (and thus should not be routinely encouraged), nor do they enhance quality of life.<sup>6</sup> Clinical experience in treating end-of-life Alzheimer's patients reveals that they often go through a period of involution where they "shut down" in terms of cognition and function (and even swallowing function) leading to Alzheimer's Cachexia. Consequently, patients with end-stage Alzheimer's will slow down and eventually stop eating solids and drinking fluids, effectively forgetting how to swallow or becoming unable to swallow (with dysphagia). The resultant dehydration and malnourishment and inanition with weight loss and decreased mental status are properly viewed as part of the natural death in these circumstances and in no way is tantamount to "starving" or "thirsting a patient to death."

In fact, the standard of care that has survived ethical and legal analysis is to simply offer these end-of-life frail, demented patients the kinds of food they like and not to force feed them. In other

words, if they like ice cream, Top Ramen Noodles, or a "Big Texas Sticky Bun," then these are the kinds of foods to be offered. Moreover, patients who have previously presumably declined an artificial feeding tube or an IV have the right to refuse the offer of food. In end-stage dementia, these patients typically stop eating food and drinking fluids quite naturally following the trajectory of their underlying dementia/frailty disease curve at their EOL phase. In a recent *New York Times* article,<sup>7</sup> *comfort feeding* is the term used to describe the compassionate and clinically pragmatic way of feeding these advanced demented patients "what they want and when they want it, never forcing them to eat or drink."

As a second example, consider a scenario in which someone prevails upon the police or district attorney to investigate "elder abuse" based upon visible bruising on the patient. Such evidence of physical trauma may support the filing of charges in other criminal cases, but in elder end-of-life care cases such markings have a far different meaning. In a case involving the end stages of a disease (e.g., terminal cancer or multiple, advanced chronic diseases causing multi-system organ failure), the skin breaks down, even with meticulous care, and creates Terminal Skin Failure, as another organ system predictably fails. In fact, the Kennedy Ulcer, classically a butterfly-like pressure type ulcer on the lower back, may be used as a marker and a prognosticator of terminal disease, classically forming only during the last 48 hours of life. Other examples, such as apparent deep tissue injury (DTI) as well as spontaneous, rapidly progressive cutaneous wounds, have been routinely discovered on close inspection by treating and hospice physicians, medical directors, families, and hospice field nurses. These wounds and DTI are considered to be consistent with classic end-of-life trajectory (from the inevitable eventual loss of lean body mass with associated cachexia due to protein energy malnutrition)<sup>8</sup> without other corroborating factors being present.

Prosecutors, unfortunately, are charging "legally naïve" lay caregivers, who themselves are suffering from unacknowledged cases of "caregiver burnout," for alleged crimes ranging from aggravated abuse to homicide due to the opinions of misinformed and inexperienced criminal and civil investigators, medical examiners, and forensic pathologists who do not possess the requisite clinical forensic knowledge, training, and experience in end-of-life

care cases. In many of these cases, the lay family caregivers are typically suffering from signs and symptoms of caregiver burnout that often are overlooked, according to the commonly used questionnaire from the AMA. This serves to burden and damage these key allied family members further and even serves to further cloud their judgment as primary caregivers in the home setting.

## The Fenn Case

In noted South Florida homicide trial *State of Florida v. Fenn*,<sup>9</sup> a recently transplanted European daughter and son-in-law were arrested, incarcerated, and charged with first degree murder in their care and treatment of a demented, debilitated, home-bound, 89-year-old Austrian woman with end-stage Alzheimer's disease with behavioral disturbance. As the family primary caregivers administering EOL care, they had insufficient knowledge and experience to handle the situation. At the outset, it appeared the treatment and conditions in which the patient lived her final days seemed cruel and unusual. Upon closer examination by the defense expert (one of the authors of this article), the expert was able to explain that these living conditions were consistent with a very common approach for someone with end-stage Alzheimer's disease.

For example, the prosecution elicited testimony that the 89-year-old decedent was kept in a feces-covered, locked bedroom that had scratch marks in the drywall. The state contended that an autopsy showed she died of starvation and dehydration. The defense expert opined that keeping her in a locked room and allowing her to refuse meals was a common approach by less than skilled caregivers but that the patient, up until the last few days of her life, did not have any bed sores or any infections. He said they could have better managed her incontinence by offering foods she could easily tolerate on a regimented schedule. The fact that she refused food was a very common sign in end-stage Alzheimer's disease. The date of the 89-year-old's death would have been the same whether or not the defendants sought medical care. If she had been taken to the hospital, she would have died there; this would have directly contradicted her explicit wish to stay at home without IVs, artificial tubes, and medical equipment. The expert further opined that there was virtually no chance she would have bounced back.

NACDL Life Member Michael Salnick of West Palm Beach, Fla., represented the defendants. He stated: "This case could really impact anyone of us any time we take care of our parents. God forbid you don't call a doctor and do it yourself. You could be accused of a crime."

Although charged with first degree murder, the jury ultimately found the defendants guilty of culpable negligence, a first degree misdemeanor in Florida; they received time served. They were also found guilty of the lesser offense of abuse of an elderly person and sentenced to five years. With over three years in, defendants hope to be released before Christmas 2010.

It was a very big victory to get the judge to give the culpable negligence charge. The defense battled with the prosecutor over this charge. After the judge read the applicable case law argued by counsel, however, the court was persuaded that the instruction was proper in this case.

In these cases it would seem appropriate to get as many instructions that steer the case to the negligence aspect as much as possible. The focus of the defense is to show no elder abuse took place and that the circumstantial evidence pointing to abuse is also likely to point to the physical end-of-life symptoms associated with the illness. At best, the defense attorney is trying to show that the defendant did all he or she could do to care for the decedent. At worst, the attorney wants jury members to believe that the defendant was negligently culpable if they are going to allocate fault.

State statutes criminalizing elder abuse will be the foundation used by the prosecution to support the murder or manslaughter charges. Some states, like California, have special statutory language that will trigger harsher punishment.<sup>10</sup>

## Conclusion

These cases are often going to turn on the care received by the decedent, which in turn is going to turn on the quality and forensic abilities of the defense expert. Defense attorneys facing such a case are best advised to seek out a qualified doctor and caregiver in end-of-life care. Surprisingly, there are not that many of these experienced practitioners around.

The combination of medical advances prolonging life and the aging of "baby boomers" is leading to an aged population of epic proportions in the United States. What is a natural death? This question will become more impor-

tant as resources (financial, emotional, governmental, and otherwise) are strained to accommodate this new circumstance. As it is, the increase in criminal prosecutions for elder abuse and homicide requires that the defense of these cases include evaluation in light of geriatric and palliative medical principles. This, in turn, necessitates the consultation of a qualified and nationally board-certified medical expert who has the requisite knowledge, training and experience in these disciplines. In fact, in the future, it is clear that "clinical forensic medicine" will play a large and expansive role in fairly adjudicating these matters with juries in U.S. courts of law.

## Notes

1. Gary W. Small, et al., *Diagnosis and Treatment of Alzheimer's Disease and Related Disorders: Consensus Statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society*, 278 J. AM. MED. ASS'N 1363 (1997).

2. This demonstrative statement was made during the discovery deposition conducted by defense attorney Michael Salnick (under oath and contained on the transcript) leading up to the Kerstin Fenn trial in West Palm Beach, Fla. Dr. Vincent Demaio acted as the state's forensic pathology expert; Michael Baden, M.D., served as the forensic pathology expert for the defense.

3. Illustrations of frailty/dementia trajectory of decline in Figures 1-3 are used by the Palliative Care Policy Center - Rand Health White Paper [WP-137(2003)] "Living Well at the End-Of-Life: Adapting Health Care to Serious Chronic Illness in Old Age" The Washington Home Center for Palliative Care Studies. Refer to pg 8.

4. EUGENIA THOENEN, WEST VIRGINIA DEPARTMENT OF HEALTH AND HUMAN RESOURCES, DEMENTIA: THE GROWING CRISIS IN WEST VIRGINIA (2005); available at <http://www.wvdhhr.org/bph/oehp/hsc/dementia/default.htm>.

5. *Id.*

6. Hospice & Palliative Nurses Association (HPNA), *HPNA Position Statement: Artificial Nutrition and Hydration in End-Of-Life Care* (2003).

7. Roni Caryn Rabin, *Feeding Dementia Patients With Dignity*, N.Y. TIMES, August 3, 2010, at D6.

8. Robert H. Demling, M.D., *Protein Energy Malnutrition and the Nonhealing Cutaneous Wound*, available at <http://www.eplasty.com/images/PDF/ProteinEnergyMalnutrition1.pdf>.

9. *State of Florida v. Fenn*, No. 06CR010990BMB, Palm Beach County (Fla. 15th Jud. Cir. Ct. Sept. 2009).

10. CAL. PENAL CODE §1203.09: (a) Notwithstanding any other law, probation shall not be granted to, nor shall the execution or imposition of sentence be suspended

ed for, any person who commits or attempts to commit one or more of the crimes listed in subdivision (b) against a person who is 60 years of age or older; or against a person who is blind, a paraplegic, a quadriplegic, or a person confined to a wheelchair and that disability is known or reasonably should be known to the person committing the crime; and who during the course of the offense inflicts great bodily injury upon the person. ■

## About the Authors

James Farragher Campbell is the founding partner of Campbell, DeMetrick & Jacobo, a San Francisco firm engaged exclusively in the defense of criminal cases. Campbell served two terms on the NACDL Board of Directors and was awarded five NACDL president's commendations. He is a past president of the American Board of Criminal Lawyers.

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