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Health Law: Physician Aid in Dying and Assessment of Patient Capacity

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Health Law

Physician Aid in Dying and Assessment of Patient Capacity

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Introduction

In 1997, the U.S. Supreme Court held that states may constitutionally prohibit physicians from providing a lethal prescription to terminally ill patients who request aid in dying.[2] Yet despite their authority to retain the prohibition, nine states (California, Colorado, Hawaii, Maine, Montana, New Jersey, Oregon, Washington, Vermont) and the District of Columbia permit "physician aid in dying" ("PAD").[3]

Oregon's Death with Dignity Act,[4] the paradigm PAD statute, allows a patient diagnosed with a "terminal" (that is, "incurable and irreversible") disease, whose life expectancy does not exceed six months, to request a lethal prescription for self-administration "for the purpose of ending his or her life in a humane and dignified manner."[5] The statute includes a panoply of procedural and substantive safeguards, seeking to enhance and support patients' end-of-life choices while protecting them from coercion and unwise personal decisions. All other U.S. jurisdictions permitting PAD have closely followed the Oregon model.

One of the most important protections for patients seeking PAD is the requirement of informed consent. This requirement seeks to ensure that patients consenting to PAD are fully informed of their choices, act voluntarily, and are legally competent to choose. It explicitly prohibits PAD for persons whose decisionmaking is impaired due to depression or other mental disorders. This Chapter reviews and interprets PAD provisions

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[1] Excerpted and adapted from Lois A. Weithorn, *Psychological Distress, Mental Disorder, and Assessment of Decisionmaking Capacity Under U.S. Medical Aid in Dying Statutes*, 71 HASTINGS L.J. 637 (2020).

[2] Glucksberg v. Washington, 521 U.S. 702 (1997); Vacco v. Quill, 521 U.S. 793 (1997).

[3] Weithorn, *supra* note 1, at 644–46.

[4] OR. REV. STAT. §§ 127.800–.897.

[5] *Id.* §§ 127.800(12), 127.805.

addressing patient competence within the context of applicable legal doctrine and scientific findings.

Patient Decisionmaking Competence Under PAD Statutes

The doctrine of informed consent establishes individuals' legal authority to make decisions about their own healthcare. Underlying and animating the doctrine is respect for autonomy,[6] which highlights the values of personal choice and "self-rule that is free from both controlling interferences by others and . . . limitations such as inadequate understanding that prevents meaningful choice."[7] In order to achieve its promise, the doctrine requires that consent be *informed* (rendered only after communication by the healthcare provider of legally required elements of disclosure),[8] that decisions be made *voluntarily* (free from coercive or controlling influences)[9] and that patients make the decisions *competently* (with the capacity to understand and reason about the information provided).[10]

Four standards of competence prevail in American law, the most common one of which is *understanding* of the information communicated by the practitioner.[11] The other three standards that appear in statutes or case law focus on patients' *ability to communicate a choice* among the treatment options; *ability to reason* about the treatment information provided; and *ability to*

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[6] Tom L. Beauchamp, *Autonomy and Consent*, *in* THE ETHICS OF CONSENT: THEORY AND PRACTICE 55, 58–61 (Franklin G. Miller & Alan Wertheimer eds. 2010).

[7] TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 101 (7th ed. 2012).

[8] AM. MED. ASS'N CODE OF MED. ETHICS 2.1.1.

[9] *See* Paul S. Appelbaum, Charles W. Lidz & Robert Klitzman, *Voluntariness of Consent to Research: A Conceptual Model*, 39 HASTINGS CTR. RPT. 30, 32 (2009); Robert M. Nelson, Tom Beauchamp, Victoria A. Miller, William Reynolds, Richard F. Ittenbach & Mary Frances Luce, *The Concept of Voluntary Consent*, 11 AM. J. BIOETHICS 6 (2011).

[10] *See* THOMAS GRISSO & PAUL S. APPELBAUM, ASSESSING COMPETENCE TO CONSENT TO TREATMENT: A GUIDE FOR PHYSICIANS AND OTHER HEALTH PROFESSIONALS 31–60 (1998).

[11] *See* Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 NEW ENG. J. MED. 1834, 1836 tbl.1 (2007).

appreciate the likely consequences and implications of the treatment options as applied to the patient's own condition and situation.

All PAD statutes require, with fairly consistent criteria, that practitioners certify that the patient is capable of making healthcare decisions. Oregon defines decisionmaking capacity as: "the ability to make and communicate health care decisions to health care providers."[12] Oregon further specifies that an "informed decision" is

> *based on* appreciation of the relevant facts and after being fully informed by the attending physician of: (a) His or her medical diagnosis; (b) His or her prognosis; (c) The potential risks associated with taking the medication as prescribed; (d) The probable result of taking the medication to be prescribed; and (e) The feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control.[13]

If conditions indicate that the patient may not have decisional capacity, but the patient still seeks PAD, the physician must refer the patient to a mental health professional for further assessment of capacity, with no life-ending drugs provided until that consultant "determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment."[14] This formulation defines a two-pronged test: (1) whether the patient is experiencing a disorder or depression; *and* (2) whether any such observed disorder or depression is causing impaired judgment. None of the statutes makes the presence of a mental disorder dispositive of incapacity; the disorder or condition also must cause impaired judgment. "Impaired judgment," as defined in the Vermont statute, exists

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[12] OR. REV. STAT. § 127.800 § 1.01(3). Other PAD jurisdictions have similar definitions. *See* COLO. REV. STAT. § 25-48–102(10); D.C. CODE § 7-661.01(2); ME. STAT. § 22-2140(2)(C); N.J. STAT. § 26:16-3; VT. STAT. § 18-5281(2); WASH. REV. CODE § 70.245.010(3).

[13] OR. REV. STAT. § 127.800(7) (emphasis added). Other PAD jurisdictions have similar provisions. *E.g.*, CAL. HEALTH & SAFETY CODE § 443.1.

[14] OR. REV. STAT. § 127.825. *Cf.* CAL. HEALTH & SAFETY CODE §§ 443.1–443.5 (providing similarly).

when "a person does not sufficiently understand or appreciate the relevant facts necessary to make an informed decision."[15]

The Legal Presumption of Competence

Under modern legal standards, adults are presumed competent to make treatment decisions, irrespective of a diagnosis of a mental or physical disorder, and despite the concern that persons dying from a terminal disease may be prone to depression or other mental disorders likely to affect their decisional capacity.

In the United States, modern law recognizes "a rebuttable presumption affecting the burden of proof that all persons have the capacity to make decisions and to be responsible for their acts or decisions."[16] This presumption for *all* persons applies to those with mental disorders, mental disabilities, or cognitive impairments.[17]

The presumption can be overcome not by resort to diagnoses or labels, but only by a direct criterion-relevant assessment of the person's *functional abilities*.[18] Decades of research on the assessment of treatment-decisionmaking competence have led to a number of empirically developed assessment guidelines and tools, such as those developed by the MacArthur Treatment Competence Study team.[19]

The MacArthur Treatment Competence Study, the seminal study in the field, compared the decisionmaking competence of three groups of recently hospitalized patients, using measures that operationalized the standards of competence defined above. The

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[15] VT. STAT. § 18-5281(5). *Cf.* CAL. HEALTH & SAFETY CODE § 443.1(i) (implying a similar definition).

[16] THOMAS GRISSO, EVALUATING COMPETENCIES 392 (2d ed. 2003).

[17] GRISSO & APPELBAUM, *supra* note 10, at 18–19. *Cf.* CAL. WELF. & INST. CODE § 5331 ("No person may be presumed to be incompetent because he or she has been evaluated or treated for mental disorder or chronic alcoholism, regardless of whether such evaluation or treatment was voluntarily or involuntarily received.").

[18] SCOTT Y. KIM, EVALUATION OF CAPACITY TO CONSENT TO TREATMENT AND RESEARCH 11 (2010).

[19] THOMAS GRISSO & PAUL S. APPELBAUM, MACARTHUR COMPETENCE ASSESSMENT TOOL FOR TREATMENT (MACCAT-T) (1998); PAUL S. APPELBAUM & THOMAS GRISSO, MACCAT-T: THE MACARTHUR COMPETENCE ASSESSMENT TOOL FOR CLINICAL RESEARCH (2001).

patients in the three groups of were diagnosed with schizophrenia or schizoaffective disorder, major depression, and ischemic heart disease.[20] These patients were compared with a group of healthy persons from the community. Impairments in performance were "more pronounced and more consistent across measures for the schizophrenia patients," with approximately 25% of the schizophrenic group scoring in the "impaired" range on each measure of capacity compared to 5–7% of the heart disease patients and 2% of the community group. Notably, approximately 50% of the patients with schizophrenia and 75% of the patients with depression revealed adequate performance *across all competence measures*. Adequate performance increased to 75% and 90% in those two groups, respectively, on the most commonly used legal standard of competence—understanding.[21] Subsequent studies by other researchers report strikingly consistent results.

The scientific literature reveals that, while chronic psychotic disorders present a risk of incompetence, "there is tremendous heterogeneity in that group," with many such patients performing quite well on competence measures initially, and others improving performance with supportive interventions to promote competence.[22] Mild and moderately depressed individuals generally meet competence standards, as do most severely depressed persons. These findings underscore the importance of individualized assessments of patients whose competence is uncertain, examining those capacities implicated by the legal standards.

Characteristics and Psychological Functioning of Patients Seeking PAD

The website of the Health Authority of the State of Oregon offers the most substantial body of data about the persons who seek PAD in the United States.[23] Data from the other jurisdictions

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[20] Thomas Grisso & Paul S. Appelbaum, *The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments*, 19 L. & HUM. BEHAV. 149, 150 (1995).
[21] *Id.* at 169.
[22] KIM, *supra* note 18, at 45–50.
[23] OREGON HEALTH AUTHORITY, OREGON DEATH WITH DIGNITY ACT: 2018 DATA SUMMARY 4 (2019).

authorizing PAD are consistent with those reported by Oregon. The cumulative 20-year Oregon data reveal that most patients who have used PAD are age 65 and older (73%) with a median age of 72 years, are White (96%), and have had at least some college education (73%).[24] Most (90%) were enrolled in hospice, and almost all (99%) were covered by either private or public insurance. The most common qualifying medical conditions included cancer (76%), neurological diseases such as amyotrophic lateral sclerosis (11%), cardiac disease (9%); and respiratory disease (8%). Patient reasons for seeking PAD were primarily psychological and psychosocial: loss of autonomy (95%), lessened ability to engage in life activities (95%), and loss of dignity (79%). Other concerns included loss of control of bodily functions (56%), possible burdens on family, friends, and caregivers (52%), worries about inadequate pain control (30%) and financial implications of treatment (5%). Oregon reports that 5% of the patients who ultimately died from PAD had been referred for mental health evaluation and found competent by the consulting mental health professional. Oregon does not report data on patients who requested PAD but were found not to be competent after a mental health referral.

According to the scientific literature, persons in the later stages of terminal disease experience emotional suffering to a greater extent than do persons in the general population.[25] It is unclear, however, whether those with such serious diseases experience a higher prevalence of mental disorder. Reported prevalence of diagnosable mental disorders varies.[26] Investigators

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[24] *Id.* at 8 tbl.1.

[25] *See, e.g.*, Harvey Max Chochinov, *Psychiatry and Terminal Illness*, 45 CAN. J. PSYCHIATRY 413, 146–48 (2000); Katherine LeMay & Keith Wilson, *Treatment of Existential Distress in Life Threatening Illness: A Review of Manualized Interventions*, 28 CLINICAL PSYCHOL. REV. 472, 472 (2008); Wendy G. Lichtenthal, Matthew Nilsson, Baohui Zhang, Elizabeth D. Trice, David W. Kissane, William Breitbart & Holly G. Prigerson, *Do Rates of Mental Disorders and Existential Distress Among Advanced Stage Cancer Patients Increase as Death Approaches?* 18 PSYCHO-ONCOLOGY 50, 54 (2009).

[26] *See, e.g.*, Robert L. Fine, *Depression, Anxiety, and Delirium in the Terminally Ill Patient*, 14 BAYLOR U. MED. CTR. PROC. 130, 130 (2001) (citing reports of incidence of major depression in terminally ill patients ranging from 25% to 77%).

report challenges of distinguishing between the presence of a mental disorder and the psychological distress attendant to the grief, loss, and suffering that often accompanies the dying process.[27] According to some studies, a subset of patients who request and receive PAD appear to their physicians to be depressed or to meet certain clinical criteria of depression. "[P]hysicians may reason that it is normal to be depressed or may be unable to distinguish depression from sadness under circumstances of terminal illness." Or physicians may believe "that depression was not interfering with decisional capacity and was not the primary reason for the request."[28] Clearly, criterion-relevant assessments of decisionmaking capacity are necessary to ensure that depressive, or any other psychological, symptoms do not impair decisional competence, regardless of the source of those symptoms.

Distinguishing Choosing PAD from a Desire to Commit Suicide

The term "physician assisted suicide," used by some to refer to PAD, has been rejected by all PAD jurisdictions. Mental health experts define suicide as a form of self-destruction of a life that was not otherwise ending. Experts note that suicide is frequently a manifestation of psychopathology.[29] By contrast, PAD assists patients in exerting some measure of control over the timing and manner of an already-impending death that will occur within six months due to a terminal illness. As one team of mental health professionals puts it: "[S]uicide is defined by the act of intentional

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[27] Susan D. Block, *Assessing and Managing Depression in the Terminally Ill Patient*, 132 ANNALS INTERNAL MED. 209, 209–10 (2000); Eric W. Widera & Susan D. Block, *Managing Grief and Depression at the End of Life*, 86 AM. FAM. PHYSICIAN 259, 259 (2012).

[28] Diane E. Meier, Carol-Ann Emmons & Ann Litke, *Characteristics of Patients Requesting and Receiving Physician-Assisted Death*, 163 ARCHIVES INTERNAL MED. 1537, 1538 (2003); Linda Ganzini, Elizabeth R. Goy & Stephen K. Dobscha, *Prevalence of Depression and Anxiety in Patients Requesting Physicians' Aid in Dying: Cross Sectional Survey*, BMJ, Aug. 2018, at 1.

[29] *See* AM. ASS'N OF SUICIDOLOGY, STATEMENT OF THE AMERICAN ASSOCIATION OF SUICIDOLOGY: "SUICIDE" IS NOT THE SAME AS "PAD" (2017).

self-inflicted death, [whereas, when patients seek PAD,] the primary (although not proximal) cause of death is from a foreseeable underlying terminal illness."[30]

Distinguishing between a desire to die grounded in the psychopathology of depression and a desire to die grounded in physical, emotional, and spiritual suffering caused by the terminal illness and impending death can be difficult even for mental health professionals.[31] The legally relevant question, however, is whether the patient's treatment decisionmaking capacity is impaired. A careful criterion-relevant assessment of the decisionmaking capacity of those persons who are suspected of manifesting such impairment is needed to separate out those who do not meet the legal standards of competence set forth in the governing statutes.

The Possibility of Neurocognitive Impairments in Patients Seeking PAD

Although the PAD statutes direct attention to mental disorders and depression, persons who are medically eligible for PAD may be more likely to experience impairments in decisionmaking capacity due to *neurocognitive limitations*. Several factors explain why this population may be at greater risk than the general population for neurocognitive impairment.

A recent study estimated the rate of dementia in persons ages 71 and older to be 14%.[32] The median age of persons receiving PAD in Oregon is 72. Persons over age 65 do not necessarily experience cognitive declines that affect treatment

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[30] *See* Dan Nguyen & Joe Yager, *PAD: Ethical and Practical Issues for Psychiatrists*, PSYCHIATRIC TIMES (Dec. 20, 2018). *See also* John Michael Bostwick & Lewis M. Cohen, *Differentiating Suicide from Life-Ending Acts and End-of-Life Decisions: A Model Based on Chronic Kidney Disease and Dialysis*, 50 PSYCHOSOMATICS 1 (2009).

[31] Elizabeth Goy, Linda Ganzini & Tony Farrenkopf, *Mental Health Consultation*, *in* THE OREGON DEATH WITH DIGNITY ACT: A GUIDEBOOK FOR HEALTH CARE PROFESSIONALS (2008).

[32] B.L. Plassman, K.M. Langa, G.G. Fisher, S.G. Heeringa, D.R. Weir, M.B. Ofstedal, J.R. Burke, M.D. Hurd, G.G. Potter, W.L. Rodgers, D.C. Steffens, R.J. Willis & R.B. Wallace, *Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study*, 29 NEUROEPIDEMIOLOGY 125, 125 (2007).

decisionmaking, but they experience a higher incidence of cognitive impairment than do younger persons, and that incidence increases with age.[33] Clinicians tasked with evaluating capacity under PAD statutes must not, of course, substitute presumptions related to age or diagnosis of a neurocognitive condition for a criterion-relevant evaluation of capacity. Stereotypes of the functional abilities of older persons can and must be avoided. Yet assessment of treatment competence may be warranted in individual cases.

A growing body of literature examines the treatment decisionmaking capacity of older persons.[34] Patients diagnosed with neurocognitive disorders exhibit substantial individual variability in decisionmaking capacities. Even within the population of persons diagnosed as having Alzheimer's Disease, "there is sufficient heterogeneity such that one cannot simply equate dementia with incapacity."[35] Research reveals that most persons with mild dementia meet legal standards of competence, particularly with additional supports to compensate for areas in which there may be deficits.

Patients with certain terminal illnesses may be at higher risk than the general population of experiencing impairments in cognition.[36] Some of these effects may be caused by the progress of the terminal disease itself, which may interfere with brain

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[33] María M. Corrada, Ron Brookmeyer, Annlia Paganini-Hill, Daniel Berlau & Claudia H. Kawas, *Dementia Incidence Continues to Increase with Age in the Oldest Old: The 90+ Study*, 67 ANNALS NEUROLOGY 114, 114 (2010).

[34] *See, e.g.*, Scott Y.H. Kim, Jason H.T. Karlawish & Eric D. Caine, *Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons*, 10 AM. J. GERIATRIC PSYCHIATRY 151, 159–60 (2002); Jennifer Moye, Daniel C. Marson & Barry Edelstein, *Assessment of Capacity in an Aging Society*, 68 AM. PSYCHOLOGIST 158, 158, 167 (2013).

[35] KIM, *supra* note 18, at 42.

[36] Moises Gaviria, Neil Pliskin & Adam Kney, *Cognitive Impairment in Patients with Advanced Heart Failure and Its Implications on Decision-Making Capacity*, 17 CONGESTIVE HEART FAILURE 175, 175 (2011); Brooke Myers Sorger, Barry Rosenfeld, Hayley Pessin, Anne Kosinski Timm & James Cimino, *Decision-Making Capacity in Elderly, Terminally Ill Patients with Cancer*, 25 BEHAV. SCIS. & L. 393, 393 (2007).

functioning or cause cognitive deterioration. Chemotherapy and radiation treatments may have a deleterious impact on cognitive functioning.[37] Furthermore, recent studies reveal manifestations of cognitive impairment in hospice patients where clinical staff have not diagnosed or treated such conditions.[38] Studies using the MacArthur measures of treatment competence demonstrate significant variability across hospice patient populations.[39]

The relationships between cognitive impairment and treatment decisionmaking in persons at the end of life constitutes a new area of inquiry, and there remains much to learn. As in the case of mental disorders, a criterion-relevant, individualized assessment is essential to determine whether a neurocognitive limitation impairs treatment decisionmaking capacity. Even diagnosis of a neurocognitive condition does not necessarily render an individual unable to meet competence standards. It is also possible that supportive interventions, such as educational or pharmacological interventions, may improve decisionmaking capacity.[40]

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[37] J. Cara Pendergrass, Steven D. Targum & John E. Harrison, *Cognitive Impairment Associated with Cancer: A Brief Review*, 15 INNOVATIONS CLINICAL NEUROSCI. 36, 37 (2017); *see also* Ian F. Tannock, Tim A. Ahles, Patricia A. Ganz & Fritz S. Van Dam, *Cognitive Impairment Associated with Chemotherapy for Cancer: Report of a Workshop*, 22 J. CLINICAL ONCOLOGY 2233, 2233 (2004).

[38] Cynthia Z. Burton, Elizabeth W. Twamley, Lana C. Lee, Barton W. Palmer, Dilip V. Heste, Laura B. Dunn & Scott A. Irwin, *Undetected Cognitive Impairment and Decision-Making Capacity in Patients Receiving Hospice Care*, 20 AM. J. GERIATRIC PSYCHIATRY 306, 306 (2012); S.A. Irwin, C.H. Zurhellen, L.C. Diamond, L.B. Dunn, B.W. Palmer, D.V. Jeste & E.W. Twamley, *Unrecognised Cognitive Impairment in Hospice Patients: A Pilot Study*, 22 PALLIATIVE MED. 842, 842 (2008).

[39] Elissa Kolva, Barry Rosenfeld, Robert Brescia & Christopher Comfort, *Assessing Decision-Making Capacity at End of Life*, 36 GEN. HOSP. PSYCHIATRY 392 (2014); Elissa Kolva, Barry Rosenfeld & Rebecca Saracino, *Assessing the Decision Making Capacity of Terminally Ill Patients with Cancer*, 26 AM. J. GERIATRIC PSYCHIATRY 523 (2018).

[40] *See, e.g.*, Laura B. Dunn & Dilip V. Jeste, *Enhancing Informed Consent for Research and Treatment*, 24 NEUROPSYCHOPHARMACOLOGY 595, 595 (2001).

Emerging Approaches to Evaluating Decisional Capacity in Patients Seeking PAD

The University of California San Francisco Medical Center ("UCSFMC") has developed an evidence-based assessment protocol to conduct mental health evaluations of persons requesting lethal prescriptions under California's End of Life Option Act.[41] UCSFMC requires all patients who seek PAD to be evaluated by the mental health team even though California law does not require this step for all patients. UCSFMC made this policy because of the centrality of this assessment to the statutory requirements. Five of the first six patients evaluated were determined to be capable under the statute; the sixth person was not found to be capable. The authors conclude: "Mild to moderate depressive disorder typically does not affect cognitive status so profoundly as to render a patient incapable of decisional capacity, even for [PAD]. Similarly, mild cognitive impairment . . . may be compatible with intact decisional capacity for [PAD]."[42]

Conclusion

In the past fifty years, the law governing patients' choices regarding their own medical care has shifted dramatically. Justice Cardozo's famous words—"[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body"[43]—emphasize that the *right* to make personal healthcare decisions depends on one's *capacity* to make those choices. Without capacity, the value of autonomy is questionable, and the state's interest in protecting those who cannot decide wisely for themselves outweighs a patient's right to choose.

Oregon's experiment with PAD during the past quarter century, followed by legal reforms in nine other jurisdictions, has created a framework that promotes patient choice while screening out patients whose decisional impairments render them incompetent to choose. Findings from scientific studies suggest

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[41] James A. Bourgeois et al, *Physician-Assisted Death Psychiatric Assessment: A Standardized Protocol to Conform to the California End of Life Option Act*, 39 PSYCHOSOMATICS 441, 441 (2018).
[42] *Id.* at 449.
[43] Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914).

that most persons seeking PAD will not demonstrate impaired judgment when evaluated with criterion-relevant capacity measures. However, further research is needed to better understand the relationships among decisional capacity and the range of factors that lead to cognitive challenges in persons who meet medical eligibility for PAD.

While it is important not to presume incapacity based on the presence of a mental disorder, psychological symptoms, or depression, it is also important that the psychological suffering and mental health challenges of persons requesting PAD be identified when they exist. To the extent that these experiences and conditions impair capacity to decide regarding PAD, such information is relevant to that person's eligibility under the statutes. Yet even for persons who meet statutory capacity requirements (whether or not they meet criteria for diagnosis of a mental disorder), the PAD request provides an opportunity for healthcare personnel to offer support and services that might ease such suffering.