

# APA RESOURCE DOCUMENT

## APA RESOURCE DOCUMENT ON PHYSICIAN ASSISTED DEATH

Council on Psychiatry and Law

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*The findings, opinions, and conclusions of this report do not necessarily represent the views of the officers, trustees, or all members of the American Psychiatric Association. The views expressed are those of the authors. –APA Operations Manual*

### **INTRODUCTION**

Over the past two decades, a number of US states have enacted statutes legalizing the practice of physician-assisted death (PAD).<sup>12</sup> In 1997, Oregon passed the first statute that legalized PAD. Washington (2008), Vermont (2013), California (2015), and Colorado (2016) have followed suit. In addition, a state court ruling in Montana legalized PAD in 2009. In 2015, the Supreme Court of Canada ruled PAD to be legal and the Canadian Parliament subsequently enacted a law to implement PAD. In February 2017, PAD was legalized in the District of Columbia. Legalization of PAD has been proposed in about half of all states in recent years (for details, see [www.deathwithdignity.org](http://www.deathwithdignity.org)). There appears to be a broad movement to consider legalization of PAD that may lead to legislation in other states. In the United States, PAD statutes have been restricted to patients with terminal illness, typically defined as an illness that is irreversible and likely to lead to death within six months.<sup>3</sup>

The legalization of PAD has a variety of implications for psychiatrists and psychiatric patients. First, current and recently proposed statutes require patients to have the capacity to make the decision to die. In some cases, the attending physician will refer patients of questioned capacity to psychiatrists for consultation. In addition, recognizing that end-of-life decision-making may be complicated by depression or other mental impairments, these laws require the attending physician

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<sup>1</sup> This is a controversial topic, evoking broad ethical debate within the medical profession, and within society at large. The language used—ranging from “physician-assisted suicide (PAS)” and “euthanasia” to “physician-assisted dying” and “death with dignity”—can color the underlying moral and advocacy perspectives. For the purposes of this document, we will use the term “physician-assisted death (PAD)” in an effort to find more neutral language.

<sup>2</sup> As used in this document, PAD does not include activities currently considered as acceptable medical practice within standard palliative and hospice care (i.e., terminal sedation, withdrawal of life support, DNR orders).

<sup>3</sup> Internationally, countries such as the Netherlands, Belgium, and Luxembourg have extended PAD to non-terminally ill patients.

to evaluate patients with suspected mental disorders and, when indicated, refer patients for psychiatric assessment.

The American Medical Association (AMA) Code of Medical Ethics has taken the position that PAD “is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.” (Opinion 2.211, issued June 1994; reissued in 2016 as Opinion 5.17, available at <https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-5.pdf>). APA members are bound by the AMA Principles of Medical Ethics (Chapter 7, Section 1 of the Bylaws of the APA, May 2003). The American College of Physicians has also taken a position against the legalization of PAD (ACP Ethics Manual, Sixth Edition, 2012 available at <https://www.acponline.org/clinical-information/ethics-and-professionalism/acp-ethics-manual-sixth-edition>). In December 2016, the APA adopted a position statement on medical euthanasia holding “that a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death.”

In view of these developments, this Resource Document was developed to provide background and relevant information to APA members regarding PAD. As policymakers consider proposed PAD laws, APA members, state associations, and district branches will likely play an important role in the legislative process.

This resource document provides a summary of the current legal status of PAD in North America, followed by a review of the reported experience to date in American PAD jurisdictions. We then discuss assessment of decision-making capacity to choose PAD, and assessment of depression in the context of terminal illness and requests for PAD.

This resource document should not be interpreted as stating an official APA position on PAD.

## SUMMARY OF CURRENT LEGAL STATUS OF PAD IN NORTH AMERICA

As of April 2017, PAD has been legalized in six US states, the District of Columbia, and Canada. The statutes are summarized below.

- Oregon Death With Dignity Act
- Washington Death With Dignity Act
- California End of Life Option Act
- Vermont Patient Choice and Control at End of Life Act
- Canada: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)
- Montana effectively legalized PAS through court ruling in *Baxter v. Montana* (2009); however, there is little regulatory guidance.

- District of Columbia: Death with Dignity Act

- Colorado: End-of-Life Options Act

Oregon's Death With Dignity Act serves as a framework for later Acts, which largely mirror Oregon's statutory scheme. Some minor differences have emerged.

### **Eligibility Criteria**

PAD statutes consider an individual to be "qualified" to choose to end his or her own life if he or she meets specified requirements. All five states and the District of Columbia require that the individual be a capable/competent adult (18 years of age or older), who is a resident of the state; be determined by medical evaluation as suffering from a terminal disease; and to have made a voluntary expression of the desire to die. California further requires the individual to possess both the physical and mental ability to self-administer the lethal drug.

Canada considers a person eligible for assistance in dying if he or she is 18 years or older; eligible for government-funded health services (or would be eligible, but for any applicable minimum residency requirement or waiting period); suffering from a "grievous and irremediable medical condition"; capable of making decisions regarding his or her health; and has both made a voluntary request for aid in dying, and given informed consent to receive this aid.

### **Residency**

An individual requesting a drug for PAD must currently be a resident of the state in which he or she requests the drug. Oregon, Washington, Vermont, District of Columbia and Colorado require a physician to verify residency (Oregon and Washington specifically reference the patient's attending physician, or the doctor with primary responsibility for the patient's care). Non-exclusive lists of factors demonstrating residency are set out by Oregon, Washington, California and Colorado. These include driver's license, voting registration and evidence of property ownership or lease in the state. Only Oregon and California also list the tax return for most recent year, although this is presumptively acceptable elsewhere since valid proof is not limited to enumerated items.

In Canada, the primary medical practitioner or nurse practitioner and an additional practitioner must provide written confirmation of the patient's residency and eligibility for government-provided health services.

### **Terminal Disease**

All US states define a "terminal disease" as a medically confirmed disease which is incurable and irreversible, and which will, within reasonable medical judgment, produce death within six months. The attending (primary) physician is responsible for making the initial determination that the patient is suffering from a

terminal disease, and that determination must be confirmed by a consulting physician who is similarly qualified to make a diagnosis and prognosis of the patient's disease. California emphasizes that a consulting physician should be independent from the attending physician.

Canada utilizes the term "grievous and irremediable medical condition". One exists if the person has a serious and incurable illness, disease or disability, and is in an advanced state of irreversible decline in capability; the person is enduring physical or psychological suffering as a result of the condition, which is intolerable and cannot be relieved under conditions they feel are acceptable; and their natural death has become "reasonably foreseeable" (which does not require a prognosis with any specific length of time). Importantly, the clause regarding psychological suffering introduces an ambiguity regarding whether physician-assisted suicide would be permissible for a patient suffering from intractable depression.<sup>4</sup> Two medical or nurse practitioners are required to confirm in writing that such a condition is present.

### **Decisional Capacity**

Oregon, Washington and Vermont utilize nearly identical language to define capacity to decide to request and use PAD medications. Oregon, Vermont and the District of Columbia use the term "capable" while Washington uses "competent". Colorado specifies "in the opinion of an individual's attending physician, consulting physician, psychiatrist or psychologist, the individual has the ability to make and communicate an informed decision to health care providers."

A person will be considered capable or competent if, in the opinion of the attending and/or consulting physician, psychiatrist or psychologist, the patient has the ability to make and communicate health care decisions to health care providers, including communication through people familiar with that patient's manner of communicating. In Oregon, Vermont and Washington, the attending physician is responsible for the initial determination of capacity or competency, and the consulting physician confirms this determination. In Oregon and the District of Columbia, a court may be called on to determine competence, but is not required to do so as a matter of course.

California defines "capacity to make medical decisions" as the patient's ability—in the opinion of the attending or consulting physician, psychiatrist or psychologist—to not only make and communicate health care decisions, but also to understand the nature, consequences, benefits, risks and alternatives of those decisions. This determination is made by the attending physician and confirmed by

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<sup>4</sup> Another section of the Act states: "9.1 (1) The Minister of Justice and the Minister of Health must, no later than 180 days after the day on which this Act receives royal assent, initiate one or more independent reviews of issues relating to requests by mature minors for medical assistance in dying, to advance requests and to requests where mental illness is the sole underlying medical condition."

a consulting physician. Canada's Act does not address decisional capacity aside from requiring a patient to be "capable" of making health care decisions.

### **Informed Decision**

Each state requires that a patient's decision to request and ingest life-ending medication be informed. In all cases, the attending physician must discuss certain subjects with the patient in order for him or her to be fully informed, and it is this physician's responsibility to decide whether the patient is making an informed decision. These critical subjects for discussion are enumerated in each state statute: the patient's medical diagnosis and prognosis, the potential risks and probable result of taking the medication to be prescribed, and the feasible alternatives to taking the medication, including hospice care, comfort care and pain control. California also requires the physician to discuss with the patient the possibility that he or she may choose to obtain the medication but ultimately not take it.

Vermont includes in its statute a patient "right to information", which states that the patient is entitled to receive answers to any specific questions about the foreseeable risks and benefits of the medication without the physician withholding any information, and without regard to the purpose of the inquiries. In this way, Vermont ensures that a physician may provide complete information to the patient without being "construed to be assisting in or contributing to a patient's independent decision" to self-administer the medication.

Canada requires that two medical or nurse practitioners confirm in writing that the patient wrote and signed his or her request for aid in dying after he or she was fully informed that he or she has a grievous and irremediable medical condition.

### **Mental Health Assessments**

Oregon, Washington, California, District of Columbia and Colorado direct the attending or consulting physicians to refer patients for mental health assessment under specified circumstances. The Oregon, Washington and District of Columbia statutes require the attending or consulting physician to refer a patient for mental health assessment if either believes that the patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment. The Colorado statute specifies that if an attending or consulting physician does not believe an individual to be mentally capable of making an informed decision, then they *must* be evaluated by a mental health professional. California requires physicians to refer patients "if there are indications of a mental disorder", and is not restricted to only patients with evidence of impairment. All five jurisdictions emphasize that no medication to end life shall be prescribed until a professional determines that the patient is not suffering from a disorder causing impaired judgment.

Vermont's statute places less emphasis on mental health assessments. It simply states that before a prescription is written, a physician must either verify that the patient's judgment is not impaired or refer him or her to a psychiatrist, psychologist or clinical social worker for confirmation that his or her judgment is not impaired. Canada's law does not address mental health assessments.

### **Legal Requirements for Requests**

All five states and the District of Columbia require an oral and a written request for the prescription, and a subsequent reiteration of the oral request. Written requests must be signed and dated by the patient and witnessed by at least two individuals attesting that to the best of their knowledge, the patient is capable, acting voluntarily and not under coercive pressure to request the medication. California's language diverges slightly, requiring attestation of knowledge that the patient is of sound mind and not under duress, fraud or undue influence.

In all five states and the District of Columbia, at least one of the two witnesses to the patient's written request must not be what Vermont calls an "interested person"—the witness cannot be a relative; entitled to a portion of the patient's estate under will or law; the patient's physician; or the owner, operator or an employee of the health care facility in which the patient is receiving care. Only Vermont specifies that the witnesses must be at least 18 years of age. Oregon and the District of Columbia require that if the patient is in a long-term care facility, one witness shall be an individual designated by the facility and having qualifications specified by rule by the Department of Human Services.

Each state directs the attending physician to offer the patient the right to withdraw or rescind his or her request at any time and in any manner, regardless of his or her mental state. This is a right which does not lapse. The offer to rescind must be reiterated after the patient's second oral request for the prescription.

Canada requires a written request, signed and dated by either the informed patient—or, if the patient is unable to sign, by another person on the patient's behalf (so long as that person is 18 years or older, understands the nature of the patient's request and does not know or believe he or she stands to benefit financially or otherwise from the patient's death). The patient must be informed that he or she may withdraw the request at any time and in any manner. Immediately before medication is provided, the patient must again be notified of the opportunity to withdraw, and subsequently must expressly consent to receiving aid in dying if he or she chooses to continue with the process.

### **Waiting periods**

Oregon and Washington require that 15 days elapse between the patient's initial oral request and the writing of the prescription. Vermont, California, Colorado

and the District of Columbia specify that the 15-day waiting period is measured from the initial oral request to the time of the reiterated oral request.

With respect to written requests, Oregon and Washington require a 48-hour waiting period between the patient's signing of his or her written request and the writing of the prescription. Vermont's statute states that the physician must write the prescription no fewer than 48 hours after the last to occur of the patient's written request, his or her second oral request, and the physician's reiterated offer of the opportunity to rescind the request. California does not specify the time frame that must elapse between written request and prescription, but a California patient must complete and execute a "final attestation" form within 48 hours of scheduled administration of the drug. The District of Columbia statute states that a written request must be submitted at least 48 hours before the covered medication may be prescribed or dispensed and before the patient makes his or her second oral request.

Canada imposes a 10-day waiting period between the day the patient signed his or her request and the day medication is provided. Deviation is permitted if the two medical or nurse practitioners attesting to the patient's condition and qualification for aid in dying are of the opinion that the patient's death, or loss of capacity to provide informed consent, is imminent—any period shorter than that 10-day window.

### **Methods of Dispensing Medication**

The five states and the District of Columbia have nearly identical provisions regarding medication dispensation. So long as the attending physician complies with applicable state licensing and certification requirements, he or she may directly dispense both the end-of-life prescription and any ancillary medications prescribed to minimize the patient's discomfort. Alternatively, with the patient's consent, the attending physician may contact and deliver the prescription to a pharmacist, who will dispense the medication to the attending physician, the patient or an agent of the patient.

Canada's Act does not address the precise methods of dispensing aid-in-dying medications, but it does require the prescribing physician to notify the dispensing pharmacist of the intended use for the medication prior to dispensation.

### **Administration of Medication**

The Washington, California, Colorado and Vermont statutes contain language referring to the ultimate "self-administration" of the prescribed drug, which involves the actual act of ingesting the medication. Although Oregon's Act lacks explicit references to self-administration, it contains provisions similar to ones espoused by Washington and Vermont barring "mercy killing" and "active euthanasia" by a physician or any other third person. California specifically states

that while a person shall not be subject to liability for assisting a patient in preparing the aid-in-dying drug, assistance with ingestion is not permitted. The District of Columbia says that no person shall be liable criminally or civilly for being present when a qualified patient takes the medication. Canada's bill explicitly permits euthanasia by including in the definition of lawful medical assistance in dying "the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death".

### **Additional Responsibilities of Attending Physician**

Along with making determinations about the patient's qualification for PAD and handling drug requests and dispensation, there are other responsibilities the attending physician must fulfill. All five states and the District of Columbia require that before the attending physician writes the prescription, he or she recommends that the patient notify next of kin (but the Acts also specify that no request for PAD shall be denied if the patient is unable or refuses to do so), and counsels the patient of the importance of having someone with them when they ingest the medication and not doing so in a public place. California requires that the attending physician counsel the patient about hospice program participation and the importance of maintaining the drug in a safe and secure location until he or she chooses to ingest it. The California attending physician is also obligated to obtain confirmation from the patient outside the presence of other parties that the patient's request for medication did not arise from coercion or undue influence.

The attending physician must fulfill state-specific medical record documentation requirements throughout this process, and sign the patient's death report. Canada similarly requires physicians to provide medical records in accordance with regulations promulgated by the Minister of Health.

### **REPORTED EXPERIENCE TO DATE IN CURRENT PAD JURISDICTIONS**

As of April 2017, published data and literature is available only from Oregon and Washington, the first two jurisdictions to enact PAD statutes. There is no published literature or collected data from Montana or Vermont (Vermont maintains a general informational website: [http://healthvermont.gov/family/end\\_of\\_life\\_care/patient\\_choice.aspx](http://healthvermont.gov/family/end_of_life_care/patient_choice.aspx)), likely reflecting the small population and infrequent use of PAD in those jurisdictions. The statutes in California, Colorado, the District of Columbia and Canada have only recently been enacted, so data has yet to emerge from those jurisdictions. Over the next several years, we can anticipate significant data and published literature to be available from California (39 million residents) and Canada (36 million residents) given their large populations.

### **Reported Experience with PAD in Oregon**

In 1997 following a three year process, Oregon adopted the Death with Dignity Act (DWDA), becoming the first American state to legalize PAD. The DWDA allows terminally ill Oregon residents to obtain and use prescriptions from their physician for self-administered lethal medications. Under the Act, ending one's life in accordance with the law does not constitute suicide. The DWDA specifically prohibits euthanasia, where a physician or other person directly administers a medication to end another's life. The DWDA mandates that physicians and pharmacies provide data to the Oregon Health Authority regarding prescriptions for lethal medications. As a result, Oregon maintains the largest and most comprehensive database regarding PAD in an American state, publishing annual statistics (<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>).

As of January 2017, nearly 1750 people have received prescriptions written under the DWDA, and more than 1100 patients have died from ingesting the medications. From 1998-2013, the number of prescriptions written annually increased at an average of 12%; however, over the past three years, the number of prescriptions written increased by more than 30%, indicating a significant increase in requests under the DWDA. In 2016, 102 physicians provided prescriptions to 204 patients, ultimately resulting in 114 deaths (an additional 19 people died in 2016 ingesting medications prescribed in previous years). More than three quarters (77%) of the patients requesting PAD had cancer; 8% had amyotrophic lateral sclerosis (ALS). The three most frequently mentioned end-of-life concerns were: decreasing ability to participate in activities that made life enjoyable, loss of autonomy, and loss of dignity.

Few patients have been referred for psychiatric assessment. Between 1998-2016, a total of 57 patients (5.1%) out of 1127 who completed PAD under DWDA were referred for psychiatric evaluation; in 2016, 5 patients (3.8%) out of 133 were referred for evaluation. Oregon does not publish data regarding patients who were referred for psychiatric evaluation, but were then found ineligible or who did not ultimately receive a prescription for lethal medication under DWDA.

The Oregon Health Authority maintains a comprehensive website (<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>) regarding the DWDA, including a detailed guidebook for health care professionals updated in 2008. As the state with the longest experience with PAD, Oregon provides the context for most of the published medical literature describing the experience of American physicians and patients (Hedberg 2009; Hedberg 2003).

Psychiatrist Linda Ganzini MD has published several articles relating to physician experience with requests for PAD, including frequency of initial requests compared to final actual deaths (Ganzini 2000; Ganzini 2016). Ganzini and colleagues have published the only articles looking at the impact of depression in

Oregon requests for PAD and the attitudes of Oregon psychiatrists. Nearly all (95%) of the psychiatrists were “confident” that they could determine whether a mental disorder was impacting the decision for PAD in the context of a long term treatment relationship, but only 6 per cent were “very confident” that they could make this assessment in a single evaluation (Ganzini 1996). In a 2008 study of 58 Oregonians who requested PAD, 18 received lethal prescriptions including three patients who had met rigorous criteria for major depression. All three died by lethal ingestion within two months of the research interview, although in one case the depression was successfully treated before death and in the other two cases the patients denied that depression was influencing their decision. The authors concluded that the current practice of DWDA may fail to protect adequately some patients whose choices are influenced by depression from receiving a lethal prescription, supporting the need for more active and systematic screening and surveillance for depression to determine which patients should be referred for further mental health evaluation (Ganzini 2008). While advocating for systematic screening to determine need for further expert evaluation, Ganzini has argued against mandatory psychiatric evaluations for all individuals requesting PAD, citing challenges of true need, access, cost, and specialized expertise (Ganzini 2014).

### **Reported Experience with PAD in Washington State**

Washington State’s Death with Dignity Act, which came into force in March 2009, allows adult residents in the state with six months or less to live to request lethal doses of medication from a physician. Importantly, the law states that medications must not be prescribed to individuals “suffering from a psychiatric or psychological disorder or depression causing impaired judgment” (Steinbrook 2008). In cases where there is concern that the patient has impaired judgment due to a psychiatric disorder, the attending physician who would prescribe the lethal medication must request a psychiatric or psychological evaluation. Otherwise, no psychiatric or psychological evaluation is routinely required. Since the law’s enactment, there has been a steady rise in the number of prescriptions dispensed for PAD. In 2009, medication was dispensed to 63 individuals, 36 of whom died after ingesting the prescribed medication. By 2015 this number had risen to 213 individuals who were dispensed medication, 166 of whom died after ingestion of the medication (Washington State Department of Health data, <http://www.doh.was.gov/portals/1/Documents/Pubs>).

Few patients have been referred for psychiatric assessment. The proportion of those referred has remained roughly stable, at about 4%. Similar to Oregon, three quarters of the patients completing PAD have cancer, while approximately 10% have a neurodegenerative disorder.

Under the Washington State statute, attending and consulting physicians must verify that the patient is competent to make an informed decision before a prescription for lethal medication is written. The Washington State Psychiatric

Association does not provide any specific guidance for psychiatrists consulted to evaluate patients' capacity to participate in Death with Dignity. However, the Washington State Psychological Association does provide such guidance, which appears to be aimed at both psychologists and psychiatrists (Washington State Psychological Association, 2009).

The WSPA guidelines recommend that the evaluating psychiatrist explore the reason for the request, the patient's expectations, fears and values, and their personal assessment of quality of life. They further recommend that the psychiatrist assess whether the decision seems authentic and in keeping with the patient's long-held values. Finally, the guidelines note the importance of distinguishing between a mental disorder, such as major depression disorder or a cognitive disorder, and the effects of the terminal illness, its treatment, or normal psychological reactions in the face of terminal illness.

Washington State collects data on end-of-life concerns of participants, as reported on the After Death reporting form which is completed by the attending physician. In 2015, it was reported that 86% of patients were concerned with losing autonomy, 86% with loss of ability to engage in activities making life enjoyable, 69% with loss of dignity, 52% with being a burden on family and friends, 49% on losing control of bodily functions, 35% with inadequate pain control or concern about it, and 25% with the financial implications of treatment. A study of those requesting Death with Dignity at the Seattle Cancer Care Alliance between 2009 and 2011 found that 97.2% cited loss of autonomy as a reason for participation (Loggers 2013).

Given the very low frequency of psychiatric evaluations requested, it is hard to draw clear conclusions. Although the state keeps information regarding all requests, the identity of the physicians involved is kept confidential. It does appear that a disproportionate number of evaluations are requested from the consultation-liaison psychiatrists at the University of Washington Medical Center and the Seattle Cancer Care Alliance. When the law came into place, the psychiatry department expected to receive a large number of referrals but, as noted above, psychiatric evaluation is infrequently sought (personal communication, 2015). The consultation-liaison service created an informal support system for psychiatrists involved in these evaluations in order to provide consultation and support for difficult cases, but in practice, this was hardly used. It was noted that in at least one case, a patient died while awaiting psychiatric evaluation. In some cases, psychiatric consultation appeared to be requested when the treating physician did not feel comfortable with the patient's request, where there was a history of psychiatric illness, or where the patient did not wish their family to know (which though encouraged, is not required by law).

#### REQUESTS FOR PAD: ASSESSING COMPETENCE

As described above, the six U.S. PAD statutes as well as Canada require that the individual requesting a lethal prescription be capable of making medical decisions regarding his or her health.<sup>5</sup> In order to be capable to request physician aid-in dying through a lethal prescription, an individual must be able to make and communicate health care decisions to health care providers. Assistance with communication may be used. The California statute gives additional guidance regarding the standard for capacity to include understanding the nature, consequences, benefits, risks and alternatives of those decisions. The California statute incorporates elements of the predominant standard for capacity assessment for medical decision-making (Appelbaum 1988; Appelbaum 2007). Specifically, decisional capacity for medical decisions requires expression of a preference, a factual understanding, appreciation, and ability to rationally manipulate information in coming to a decision. The Oregon statute similarly gives guidance regarding an “informed decision” based on an appreciation of facts including diagnosis, prognosis, probable risks and results of taking the prescribed medication, and alternatives, incorporating key elements of information relevant to informed consent (Brendel 2007; Weintraub Brendel 2011).

While concepts of capacity and informed consent are generally well established, the evolution of newer practices with prominent legal and ethical features, such as PAD, add complexity to these heretofore broadly accepted frames of reference and were not well established as PAD became legally permissible (Werth 2000). Specific guidelines regarding the content of capacity determinations are absent from the Oregon statute. The Task Force to Improve the Care of Terminally-Ill Oregonians has published a useful guidebook for health care professionals, including a chapter on mental health consultation (Oregon Guidebook, 2008). Attending or consulting physicians must refer an individual seeking a lethal prescription for a mental health evaluation by a psychiatrist or psychologist if the physician believes that the patient may be suffering from a mental health disorder or depression causing impaired judgment. The task of the psychiatric (or psychological) evaluator, then, is to determine whether the patient has the ability to make and communicate health care decisions.

Amongst individual psychiatrists (and psychologists), there is a divergence of opinion regarding the ethical permissibility of PAD (Ganzini 1996; Ganzini 2000; Fenn 1999). Psychiatrists may object to participating in assessments of capacity for assisted death for conscientious reasons. In addition, forensic psychiatrists who described themselves as morally opposed to PAD were more likely to employ a stringent standard for capacity for PAD and more likely to believe that the presence of depressive symptoms would automatically render a patient lacking in capacity compared to psychiatrists who did not oppose PAD on ethical grounds (Ganzini 2000). As with all other psychiatric assessments, psychiatrists should be aware of the potential impact of both transference and counter-transference. Given the possible “high stakes” outcome of the competence assessment, it is essential that

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<sup>5</sup> Washington uses the term competence, rather than capacity, but no substantial difference is apparent.

psychiatrists be aware of their own views regarding PAD and how those views might bias an evaluation of capacity ---either as overly restrictive or overly permissive. The Oregon Task Force's guidelines for capacity assessment specifically state that mental health professionals with strong personal biases for or against PAD "should consider declining the consultation." In addition, if the psychiatrist perceives another type of conflict, financial or of another nature, the evaluation should not proceed.

According to the Oregon task force, the mental health consultant has two roles. The first role, determined by statute, is to assess the patient's specific capacity to make the decision to seek PAD. The task force also cites a second role, a traditional or clinical role, to evaluate the individual for "any remediable sources of suffering." This may include discussion of palliative care options, which may be complementary to curative and life-prolonging treatments. In the process of the capacity evaluation, consulting psychiatrists must be attuned to both roles. From an ethical perspective, this dual role is also critical to avoid the psychiatrist from becoming a gatekeeper for PAD and focus primary involvement with patients on their roles as healers (Sullivan 1998).

### **Performing the Capacity Assessment**

In terms of the capacity assessment itself, the specific components of the evaluation are not strictly defined. The Oregon Task Force describes the components of the evaluation with broad guidance. The resource document describes a process that will "usually include" record review, discussion with the referring physician, patient interview and assessment, and collateral interviews with family, caregivers, and other important persons in the individual's life. Collateral information may be critical to the evaluation, but should be obtained in accordance with established rules governing confidentiality and consent. Caregivers, especially those working in hospice settings, may be particularly attuned to fluctuations in mental status, causes, and effective remedies.

The Oregon Task Force recommends that the evaluation focus on assessment for mental disorder, decision-making capacity, and factors limiting the individual's ability to make a decision (specifically, symptoms of mental disorder, coercion, and knowledge deficits). The focus of the interview, therefore, should include particular attention to understanding risks and benefits and other possible interventions, including their likelihood of success. Capacity requires both a factual understanding and an appreciation of how facts apply to the individual's own situation (Appelbaum 1988; Appelbaum 2007; Guidebook 2008).

The Task Force reminds psychiatrists to be cognizant of how tiring an evaluation may be for a terminally ill individual and also the importance of rapport. Psychiatrists should maximize the patient's comfort and ability to demonstrate capacity and also consider the use of standardized instruments and tools. Useful instruments, according to the Task Force, may include the Geriatric Depression

Scale, the Folstein MMSE, or the Neurobehavioral Cognitive Status Examination. Ultimately, however, the Task Force concludes that, “In the absence of a mental disorder, evidence of coercion, or knowledge deficits, most patients will qualify for the Oregon Act.” Finally, according to the Oregon task force, when a psychiatrist cannot make a determination of capacity with confidence, options include recommending treatment, re-evaluations, and/or referral for additional capacity assessment.

In contrast to the general guidance offered by the Oregon Task Force, Werth and colleagues propose a more exhaustive set of guidelines for evaluation of capacity for PAD (Werth 2000). Much of the structure of the evaluation is consistent with the Oregon Task Force (e.g. record review, consultation, collateral information, use of objective assessment instruments, clinical interview and diagnostic assessment, and assessment of decisional capacity elements). However, Werth and colleagues also advocate for an in-depth exploration of the PAD decision in the context of the individual’s perceived quality of life, stated and implied reasons for requesting PAD, and an inquiry into how the decision fits into the person’s value structure and would affect others. The strength of the depth of this approach is based on the notion that it is expected to prevent erroneous granting of lethal prescriptions to incapacitated individuals. However, the specificity and depth of the requirements may have the opposite effect of limiting the availability of PAD to those who are held to too high a standard of capacity and meet adequate safeguards for self-determination by PAD.

In response to what may be perceived as the overly-demanding nature of the Werth guidelines, Stewart and colleagues (Stewart 2011) advocated for a standard essentially consistent with that developed by the Oregon Task Force. This approach draws largely on the Appelbaum-Grisso standard for capacity as well as the common law tradition of informed consent, specifically, that patients must be able to comprehend and retain information about the decision for PAD, to weigh the information and reach a decision, express a consistent preference over time, communicate choice, and be free from undue influence.

Ultimately, as PAD practice evolves, psychiatrists can play a key role in elucidating the capacity assessment process and methods of developing rapport and engaging with dying patients.

#### REQUESTS FOR PAD: ASSESSING DEPRESSION

While most individuals requesting PAD do not carry a diagnosis of depression, studies suggest that between a quarter to a half of requests came from individuals with depression (Wilson 2016; Levene 2011; Ganzini 2008). Presumably most of these individuals were nevertheless considered by their attending and consultant physicians to have decisional capacity without impaired judgment since only 5% of cases in Oregon and 4% in Washington were referred for a mental health evaluation. It is not clear if the rates of referral should be higher, or if these rates are

appropriate since these states' statutes only require evaluation by a mental health professional if there is concern that symptoms impair judgment. Nevertheless, given what is known about under-recognition and under-treatment of depression generally, more involvement with a mental health professional would likely be beneficial.

As noted previously, approximately 75% of the individuals accessing PAD in Oregon and Washington had cancer and approximately 10% had neurodegenerative disease, primarily ALS. Similar patterns are seen in other localities with different regulatory structures (Emanuel 2016). It is likely that similar clinical patterns might emerge in other states that legalize PAD. Therefore, understanding features of a desire for PAD, and more broadly a desire for hastened death, in these groups of individuals in particular will become important. Psychiatrists who perform mental health assessments for PAD will need to be familiar with the presentation of depression in the relevant patient populations.

While PAD accounts for a relatively small proportion of deaths (less than 0.4% of all deaths in both Oregon and Washington in 2015) and requests for PAD are relatively rare even in localities where PAD is legal, a more general desire for death<sup>6</sup> is not uncommon in patients with advanced life-threatening illness. Wilson and colleagues note that although studies range quite a bit in quality, researchers have found that between 11-55% of patients in palliative care settings experience such a desire at least transiently, and from 3-20% report a more pervasive and apparently sincere wish to die (Wilson 2016). Hudson and colleagues note that empirical studies of patients with advanced cancer found that approximately 8-15% of patients express an interest or a desire for hastened death and that studies with less rigorous approaches report higher levels (Hudson 2006). In two separate studies, Rabkin and colleagues found that 19% of individuals with ALS expressed a wish to die (Albert 2005; Rabkin 2015).

Regardless of the prevalence of a desire to die, depression appears to be highly correlated with it, though not universally present. Wilson and colleagues note that an association between depression and the desire for death has been found in every study that has looked at this issue, citing the prevalence of diagnosed depression among individuals expressing a desire for death has ranged from 47-80% (Wilson 2016; Periyakoil 2012; Brenne 2013; Rosenfeld 2006; Lloyd-Williams 2003; Mitchell 2008). At the same time, they emphasize that the desire for death is often surrounded by a broader context of clinically significant psychological distress and note that studies looking more in depth at how individuals arrive at a desire for

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<sup>6</sup> The literature in this area refers to similar concepts with different terminology; for example, different authors refer to "desire for death", "desire for hastened death," "thought about hastened death," "wish for death/hastened death" etc. These linguistic and in some cases conceptual differences likely account for some of the different findings among the many research studies addressing questions in this area. In this document, we use the terminology used by the authors in the studies we cite.

death have found different pathways. They conclude that the expression of a desire for death by a terminally ill patient should raise concern about the presence of mental health problems, although it is not necessarily diagnostic of active psychiatric illness (Wilson 2016). A similar conclusion is reached by Rabkin and colleagues who find that of the 62 patients in their ALS study who expressed a wish to die (19% of the study participants), only 37% (23 patients) were clinically depressed. They conclude that a wish to die is not always expressed in the context of depression and does not necessarily represent psychopathology in patients with ALS (Rabkin 2015).

Studies focusing in-depth on the *wish to hasten death*, as opposed to a more general desire for death, concur. A review of the qualitative studies of patients expressing a wish to hasten death concludes that such expressions do not necessarily imply a genuine wish to hasten one's death, but rather represent a response to overwhelming emotional distress and carry with them a variety of potential meanings (Monforte-Royo 2012). They identify six main themes giving meaning to an expressed wish to hasten death (WTHD) which they suggest should be taken into consideration when formulating treatment plans: (1) WTHD in response to physical/psychological/ spiritual suffering, (2) loss of self, (3) fear of dying, (4) the desire to live but not this way, (5) WTHD as a way of ending suffering, and (6) WTHD as a kind of control over one's life ('having an ace up one's sleeve just in case'). Despite this, many studies indicate that depression, hopelessness and a low sense of spiritual well-being are the strongest predictors of a desire for hastened death in terminally ill patients (Breitbart 2000; Albert 2005; Rosenfeld 2006; Rodin 2009). Keeping in mind the many potential contributions (including depression) to a WTHD provides for both better understanding of the context of the request and better treatment planning.

The complexity of the desire to hasten death and the variable role played by depression is just one among a variety of contributing factors, including physical symptoms (either present or foreseen), other forms of psychological distress (e.g., hopelessness, fears, etc.), existential suffering (e.g., loss of meaning in life), and social aspects (e.g. feeling that one is a burden) (Balaguer 2016). While treatment for depression is effective at reducing the symptoms of depression in these populations, it is not clear whether treating the depression changes the desire to hasten death. Some studies suggest a strong correlation between ameliorating depression and decreased desire to hasten death (Breitbart 2010; Rosenfeld 2006), while others (conducted by the same research team) do not (Rosenfeld 2014).

Thus, all clinicians working with patients who express a wish for hastened death should understand the complexity of this phenomenon and can prepare to respond in a meaningful way to patients' expressed desire for hastened death, rather than avoiding it as many do. For example, a 2006 review suggests potential approaches for health professionals to consider when faced with patients' desire to die statements (DTDS) that will enable them to manage the issue with confidence (Hudson 2006). This review includes sample phrases and questions to use when

responding to a DTDS that are culled from the literature and expert opinion covering different aspects of these expressed desires, including: (1) current feelings of fears, (2) suffering distress—physical, spiritual, psychosocial, or existential; (3) considering suicide, and (4) seeking health professional assistance with hastened death.

## **Screening Tools**

In light of the high correlation between depression and desire to hasten death in individuals with advanced illness, screening for depression in these individuals, and in particular those who express a desire for hastened death and/or PAD, should be part of any program for providing general medical care for these individuals. Indeed, though not required by statute, the Oregon Task Force recommends screening with PHQ-9 though it is not clear how widely this recommendation is followed. Other screening instruments are also available.

Vodermaier and colleagues provide an extensive review of assessment instruments used to screen for distress in cancer patients. The definition of distress includes affective disorders, anxiety disorders and adjustment disorders (Vodermaier 2009). This paper includes a review of the psychometric properties of a variety of screening tools with emphasis on their sensitivity and specificity. While short verbal scales are helpful for quick screening of depression in hospitalized patients who have difficulty with completing long questionnaires, the longer questionnaires are valuable in their ability to address multiple domains besides depression. The authors indicate that a large variety of scales of varying lengths, including the CES-D, HADS, BDI and GHQ-28 are high quality scales for screening emotional distress. They also note that while many screening tools focus on symptoms of depression, screening measures that cover multiple domains are more valuable because the psychological symptoms in terminally ill patients may vary considerably from symptoms of depression, anxiety, adjustment disorder to mixed states. They provide the psychometric properties of ultrashort, short and long screening tools and discuss the pros and cons of the different instruments.

Some studies indicate that a single question, “Are you depressed?” is an effective screening tool for depression in palliative care patients (Lloyd-Williams 2003; Chochinov 1997). However, other studies indicate that a two-question approach that includes one question about ‘depressed mood’ and another about ‘loss of interest’ is more accurate than using either question alone; if using a single question, the ‘loss of interest’ question is a better screening tool (Mitchell 2008). However, neither the single ‘loss of interest question’ nor the two question method had a case-finding accuracy of more than 60% and would thus need to be combined with a second method with better positive predictive value. This could be a clinical diagnostic interview or a structured and validated depression scale. The PHQ-9 is another short screening tool for depression that is widely used in medical settings and has been studied in the cancer patient population (Fann 2009). Thus, a step-wise approach of first using a screening tool followed by an assessment using a

validated depression scale would be an effective approach for diagnosing depression (Mitchell 2012). While the simple verbal questions and the PHQ-9 are shorter screening tools for depression, a clinician can choose from a variety of clinical tools with variable length, psychometric properties and strengths based on the need, clinical setting and objective of use (Vodermaier 2009).

Screening for other mental illnesses could also be accomplished with tools like PRIME-MD (all of these are tied to DSM-IV diagnoses). Determining an appropriate instrument for routine screening involves trade-offs between tools of reasonable length and those with adequate psychometric properties. Computerized touch screen versions of screening instruments can be used successfully by patients with advanced illness in hospice care and, when available, touch screen and autoscoring technology ensures continuity and standardization, reduces costs, and lightens the workload of clinical personnel (Vodermaier 2009). In any screening process, a decision has to be made as to the correct balance between sensitivity and specificity. Given the gravity of a PAD decision, the emphasis may be on sensitivity to minimize the number of missed cases of depression.

Regardless of which screening tool is chosen, improved outcomes are dependent on timely referral for treatment and adequate follow-up. Programs that implement routine screening must have the ability to accommodate referrals for specialty mental health care when indicated. For example, while all of the following might result in a positive screen for depression, from a diagnostic and treatment standpoint, it would be important to differentiate a diagnosis of depression from somatic symptoms of a medical condition, medication side-effects, a grief reaction and psychological distress due to the medical condition. Many health systems do not have the ability to accommodate rapid referrals for specialty mental health care that may arise from routine screening, thus complicating implementation.

As systems determine whether and how best to move towards routine screening more generally, clinicians receiving a request from a patient for PAD might consider certain “red flags” in addition to the typical neuro-vegetative symptoms of depression when deciding about further evaluation by a mental health professional. Examples include:

- Psychological symptoms: including depressed mood, tearfulness, feeling of helplessness, feeling of hopelessness, social withdrawal or isolation, lack of interest, feelings of guilt, suicidal ideation, significant anxiety;
- Somatic concerns/preoccupations which appear beyond what would be expected from the patient’s physical condition;
- Uncontrollable, poorly managed or intractable pain;
- Distress due to loss of bodily function;
- Feeling of loss of control;
- Fear of becoming a burden on others;
- Limited social supports, marital and family conflicts;

- Functional decline out of proportion to the medical situation;
- Preoccupation with financial concerns;
- Sense of therapeutic nihilism, “quickly get it over with”;
- Lack of participation in or refusal of treatment;
- Fearful or loss of hope about their future;
- Dignity related distress; and/or
- Spiritual distress.

Even when further evaluation may not lead to a diagnosis of depression or another treatable mental health problem, many of these distressing experiences could benefit from specific attention by a mental health or palliative care professional, or in some cases by a case manager or social worker. Sometimes, clinicians focused on their patients’ medical problems forget that some of their experiences may not be an inevitable part of their advanced illness and overlook the possibility that their distress might be alleviated by specialty care.

## CONCLUSIONS

This resource document is intended to provide a summary of existing PAD statutes and states’ experience related to implementation. This information may prove useful to psychiatrists, APA District Branches, and state psychiatric organizations in the event that PAD legislation is considered in their jurisdictions. We also offer a summary of relevant research on the psychiatric assessment of capacity and of depression in an effort to assist individual psychiatrists who may be asked to assess patients requesting PAD.

When reviewing this resource document, psychiatrists and policymakers should note the following limitations of the information summarized:

1. All of the currently published data about the implementation of PAD comes from Oregon and Washington State. In comparison to many other US states, these jurisdictions are relatively affluent, white, educated, and culturally homogenous.
2. The number of terminally ill individuals who have elected to seek out PAD has been small.
3. In each of those states, a small select group of attending physicians and psychiatrists has participated in PAD.
4. In those states, referrals to psychiatrists have been relatively uncommon (4-5%).

It is not known how PAD would be employed in other jurisdictions with more diverse populations. There are many potential reasons for concern. Terminally ill patients who are not affluent may be motivated to seek PAD not because they desire a more humane death, but because they cannot afford end-of-life care, have no caregivers to provide assistance, or fear burdening family and friends. It is also

likely that among less educated and economically disadvantaged populations (groups with a higher prevalence of depression and other psychiatric illness), the frequency of concerns about decision-making capacity may be higher. Moreover, in more populous states, PAD will involve a larger number of physicians with more varied approaches to capacity assessment and relevant medical assessments. Finally, we have little data about psychiatric assessments that lead to recommendations against PAD due to decisional incapacity or treatable depression. The small number of psychiatric referrals currently reported raises concerns that some instances of treatable depression or decisional incapacity are not being detected.

As our society continues to explore physician-assisted death as a legally available option, collection and analysis of vital data will be essential. We recommend that all jurisdictions follow a mandatory data collection model exemplified by Oregon. Additional information should be collected about patients referred for mental health assessment, their psychiatric diagnoses, the outcomes of referral, and subsequent outcomes. Together with well-designed clinical and health services research studies, this data will be critical to advancing our understanding of the mental health presentation of patients requesting assisted death and best practices in localities where the practice is legal.

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