## THE WASHINGTON DEATH WITH DIGNITY ACT: WASHINGTON STATE PSYCHOLOGICAL ASSOCIATION GUIDELINES FOR PSYCHOLOGICAL EVALUATIONS Revised April 2019

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### **A. Introduction**

The Washington Death With Dignity Act (2008) was passed November 4, 2008 and went into effect on March 5, 2009. If physicians have any concerns about the capacity of a patient wishing to use the law to make informed health care decisions, they must make a referral to a mental health professional, specifically a psychologist or psychiatrist, for an evaluation. In 2009, the Washington State Psychological Association (WSPA) published guidelines for psychologists serving terminally ill adults who are considering using the Washington Death With Dignity Act (Washington State Psychological Association's End of Life Committee's Death with Dignity Guidelines Task Force, 2009). This 2019 revision incorporates the years of experience of psychologists evaluating patients wishing to utilize the Death With Dignity (DWD) option in Oregon (in effect since October, 1997) and in Washington (in effect since March, 2009). The recommendations presented here serve as a complement to the Oregon Death With Dignity Act Guidebook for Health Care Professionals (Task Force to Improve the Care of Terminally Ill Oregonians, 2008, Chapter 9) and to the California's End of Life Options Act: CPA's Guidance for Psychologists (California Psychological Association End of Life Option Act Work Group, 2017). These excellent and comprehensive resources, together with the annual reports provided by the health departments of Oregon (Oregon Health Authority, 2019), Washington (Washington State Department of Health, 2018), and California (California Department of Public Health, 2018), provide a wealth of contextual information relevant to working and conducting evaluations with this population.

WSPA has been a leader among national and state psychological associations as well as other mental health organizations regarding the contributions psychology can make toward working with people near the end of life, particularly regarding physician aid-in-dying or "Death With Dignity" (DWD). In 1996, WSPA signed an amicus curiae brief submitted by a coalition of mental health professionals to the U.S. Supreme Court (Washington v. Glucksberg, 1997; Vacco v. Quill, 1997; Werth & Gordon, 2002), and subsequently signed similar briefs submitted to several courts (Miller & Werth, 2006; Tucker, 2008). These briefs presented empirical data demonstrating that psychologists have appropriate and effective diagnostic tools to assess the competence of terminally ill patients to make informed end-of-life decisions. As of this writing, DWD is legal in eight jurisdictions: Oregon, Washington, Montana, Vermont, Colorado, California, Hawaii, Washington DC, and New Jersey.

As part of the American Psychological Association's (APA) commitment to the psychological well-being of individuals across the life span, APA actively promotes the involvement of psychologists in multiple aspects of end-of-life care (APA, 2005). For comprehensive policy statements of APA's 2017 positions on DWD and on the role of psychology in end-of-life care see APA's <u>Resolution on Assisted Dying and Justification</u>

(2017b) and APA's <u>Resolution on Palliative Care and End-of-Life Issues and Justification</u> (2017c). Also see the <u>APA Aging Issues Newletter</u> for ongoing APA resources related to the end of life (APA, 2019).

#### **B.** Preliminary Considerations for Participating Psychologists

Psychologists may play many clinical roles in end-of-life care, including, but not limited to, providing treatment (psychotherapy), consultation (to medical teams, patients, and families), and evaluations for competence to make informed decisions (Weir, 2017a, Weir, 2017b).

When working with any patient facing death, but in particular before accepting a referral for evaluating a patient requesting use of Washington's Death With Dignity law, psychologists will serve the best interests of their patients by understanding the degree to which their own views might bias or limit their ability to work with dying patients, especially those requesting life-ending medications. Psychologists are urged to assess their own personal and professional beliefs, values, and cultural influences regarding dying, end-of-life choices, and end-of-life decision-making to determine whether they can be objective, nonjudgmental providers of evaluations and recommendations (Ethical Principles of Psychologists and Code of Conduct [EPPCC], APA, 2017a; Katz & Johnson, 2016). If a psychologist determines that his or her views might limit the capacity to provide an accurate, patient-centered assessment, a referral to another professional is necessary (EPPCC Standard 10.10; APA, 2017a).

Special competencies and knowledge are required on the part of psychologists who choose to conduct DWD evaluations. Although there is no certification for conducting DWD evaluations, it is essential that psychologists obtain appropriate education, training, and consultation. Psychologists must also stay informed about current palliative care and end-of-life issues, community resources, and options regarding end-of-life choices. Knowledge in the fields of health psychology, rehabilitation psychology, geropsychology, and neuropsychology is also useful. Psychologists are encouraged to see themselves as part of larger, multidisciplinary teams and to engage with and use the expertise of the other professionals involved with the patient and family.

Psychologists should avoid any type of multiple relationship when conducting DWD evaluations. Specifically, a psychologist who is seeing a patient for psychotherapy should not also be evaluating the patient for eligibility to use the law. Unless there are mitigating circumstances, the psychologist should decline to perform an evaluation when a dual relationship exists. A possible mitigating circumstance would be providing service in a rural or underserved area with limited professional options. In such an instance, the psychologist should disclose the nature of the multiple relationships to the patient and the attending physician as well as document the disclosure in the patient record.

Psychologists should be familiar with the <u>APA Ethical Principles of Psychologists and</u> <u>Code of Conduct</u> (2017a). In particular, the following sections are relevant to the practice of providing DWD evaluations:

- General Principles A–E;
- 2.01 Boundaries of Competence;
- 3.05 Multiple Relationships;
- 3.07 Third-Party Requests for Services;
- 3.09 Cooperation with Other Professionals;
- 3.10 Informed Consent;
- Section 4, Privacy and Confidentiality;
- 6.04 Fees and Financial Arrangements;
- Section 7, Education and Training;
- Section 9, Assessments;
- 10.1 Informed Consent to Treatment.

# C. Overview of Legal Duties and Responsibilities

In Washington, the attending and consulting physicians must verify that the patient is competent to make an informed decision in order for the patient to receive a prescription for lifeending medication. The definitions of competence and an informed decision are given in RCW 70.245.010, subsections (3) and (7) respectively:<sup>1</sup>

(3) "Competent" means that, in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, psychiatrist, or psychologist, a patient has the ability to make and communicate an informed decision to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available.

(7) "Informed decision" means a decision... that is based on an 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 to be 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.

In addition, RCW 70.245.060 mandates a "counseling referral" (essentially a referral for a psychological evaluation) to a licensed psychologist or psychiatrist under certain circumstances:

<sup>&</sup>lt;sup>1</sup> According to Grannum v. Berard (70 Wash.2d 304, 422 P.2d 812,1967), "[the law] will presume that every man is sane and fully competent until satisfactory proof to the contrary is presented. Washington State holds that the standard of proof required to overcome this presumption, in civil cases, is that of clear, cogent and convincing evidence" (p. 814). Under RCW 70.245.060, the physicians or psychologist/psychiatrist determine whether the patient is competent to make an informed decision.

If, in the opinion of the attending physician or the consulting physician, a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment, either physician shall refer the patient for counseling. Medication... shall not be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment.

It is important to note that the presence of depression, anxiety, or a psychiatric disorder may not preclude being qualified to use the law as long as the presence of any such symptoms does not impair judgment or competence of the patient to make an informed decision.

At the conclusion of the evaluation process, the psychologist must submit the <u>Washington State Department of Health Psychiatric/Psychological Consultant's Compliance</u> Form (Washington State Department of Health, 2016) to the referring physician. This form requires a brief summary of findings. The psychologist should also prepare a more complete report on the evaluation and findings for his or her own files (see section E below for what this report should include).

# **D.** Conducting the Evaluation

# 1. General Considerations

There is no published standard of care and there are no mandatory guidelines for conducting evaluations for eligibility to use the Death With Dignity law. The challenge for each participating psychologist will be to develop clinical protocols that are:

- consistent with his or her own style for working with patients facing end-of-life decisions;
- sensitive to the needs of individual patients, including physical and mental limitations as well as health-care needs;
- valid and reliable approaches to providing services to patients facing end-of-life decisions;
- congruent with the requirements of RCW 70.245;
- adherent to APA ethical standards.

The discussion and recommendations that follow address how to responsibly and reliably meet the mental health requirements of the law.

These suggestions are neither prescriptive nor exhaustive. It is the responsibility of the psychologist to conduct a thorough evaluation on which to base conclusions and recommendations. In addition to being accurate and comprehensive, sensitivity and compassion are key components in this process. It is essential that the evaluation be structured in way that reflects an understanding that when people are dying, they are likely to have fluctuating energy levels. Patients may be receiving treatment or medications whose side effects can compromise the amount of time they are able to participate in the evaluation and which may affect their

overall level of functioning. Finally, patients may be anxious due to the stress of being evaluated, given that the outcome of this process will be critical to how their lives will end.

A balance must be struck between not unduly burdening the patient and gathering the necessary data to determine that the patient is competent and can make an informed decision. At the conclusion of the evaluation, the psychologist must be able to document the findings that support his or her conclusions. Even if the conclusion of the evaluation is that the patient does not meet eligibility requirements to use the DWD law, it can be beneficial and even therapeutic if the experience is positive, respectful, and as least stressful as possible. In that case, the patient can then move forward with his or her attending physician and support team to consider other palliative and end-of-life care options. (For a clinical illustration, see Katz & Johnson, 2016.)

## 2. Disclosures and Patient Consent

The patient's consent for services must be obtained in writing. The following information should be disclosed to the patient orally and in writing at the outset of the evaluation:

- a. The entity or individual requesting the evaluation;
- b. The entity or individual responsible for the bill;
- c. The fee for the evaluation;
- d. The name of the attending physician who will receive the results or the report;
- e. The limits of confidentiality;
- f. The general procedures to be followed.
- 3. Sources of Information

Multiple sources of data should be used to assess a patient's competence to qualify for DWD. These sources can include:

- a. The patient's medical record and the reason for the referral. (It may not be necessary to examine the full medical record and may be sufficient to refer to the information provided by the referring physician.)
- b. Collateral interviews with various members of the patient's health care team, such as physicians, social workers, nurses, chaplains, hospice workers, psychotherapists, psychologists, etc.
- c. Face-to-face interviews with the patient. (More than one session may be necessary, and sessions may need to be conducted in the patient's home or hospital room.)
- d. Collateral interviews with individuals in the patient's social network: family, friends, caregivers, witnesses to the request for life-ending medication, those who will be present at the death, and others who could be helpful regarding religious, ethnic, and cultural issues relevant to the case. Note that the law does not require the patient to inform family

of the decision to use the DWD act.<sup>2</sup> Therefore, the psychologist must learn at the outset of the evaluation what the patient's wishes are regarding who in the family and social network is informed about this decision and maintain strict confidentiality accordingly.

- e. Previously expressed intentions of how the patient wants to be treated near the end of life. These may include, for instance, advance directives, living will, medical power of attorney, or the <u>Physician Orders for Life Sustaining Treatment—POLST</u> (Washington State Department of Public Health, 2017). (Note: it may be sufficient to inquire what the patient has stated in these documents.)
- f. Psychological testing of the patient. There is no consensus about the best way to assess a dying person's ability to make an informed decision to request life-ending medications. At present, there are no standardized test instruments proven to be valid and reliable in the assessment of capacity to make end-of-life decisions, and there are no available test measures that have been developed or normed on terminally ill patients.

The psychologist conducting the evaluation must decide on a case by case basis whether including or forgoing test measures is appropriate, relevant, or useful for the purpose of that particular evaluation. When possible, psychometric testing is to be avoided as it can be burdensome for someone who is dying. A clinical interview may be sufficient to make this determination (Block, 2000; C. DeCampos, personal communication, 2016). If the psychologist judges that there is a need to include a measure, it is recommended that the psychologist choose based on the principle that less is better.

Measures that have been used in DWD evaluations include the Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001), the Geriatric Depression Scale (GDS; Yesavage et al., 1983), the Generalized Anxiety Disorder Scale-2 (GAD-2; Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007), and the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005).

4. Competence to Make an Informed Decision

Many factors may be involved with a patient's desire to pursue DWD, and the challenge to the psychologist is to determine if any of them impair judgment or indicate that the patient lacks competence to make an informed decision. The competence to make informed medical decisions requires a demonstration of the patient's ability to:

- 1. Understand relevant information needed to make the decision;
- 2. Appreciate the consequences of different options;

<sup>&</sup>lt;sup>2</sup> RCW 70.245.080: Notification of next of kin.

<sup>&</sup>quot;The attending physician shall recommend that the patient notify the next of kin of his or her request for medication under this chapter. A patient who declines or is unable to notify next of kin shall not have his or her request denied for that reason."

- 3. Indicate a clearly held underlying set of life values that provide guidance for making the decision and are consistent with it;
- 4. Communicate the decision and explain the process for making it (Vacco v. Quill, 1997; Washington v. Glucksberg, 1997).

A tool that may be useful to the psychologist in both evaluating capacity and also in structuring a clinical interview to determine capacity in a patient facing a serious medical decision is the <u>Aid to Capacity Evaluation</u> (ACE) (University of Toronto Joint Centre for Bioethics), a protocol designed to assist health care providers evaluate capacity when a patient is facing a serious medical decision. The ACE provides useful guidelines for conducting a clinical interview to determine capacity. It includes eight questions that assess the patient's understanding of the medical problem, treatment proposed, treatment alternatives, possible consequences of the decision, and the effect of any underlying mental disorder on the patient's decision-making process.

During the clinical interview, the psychologist must determine how the patient makes sense of the reality that life is coming to an end and whether the DWD request is consistent with his or her long-held values and goals. It will be helpful to gather information about biopsychosocial factors that could shed light on the patient's (1) reasons for the request; (2) expectations, fears, values, and religious or spiritual beliefs; (3) cultural values; and (4) personal assessment of quality of life. Whether the evaluating psychologist would make the same choice for himself/herself personally is not relevant.

Observations regarding the patient's appearance, attitude, motor activity, affect, mood, speech, thought process, attention/concentration, thought content, and cognitive functioning should be noted. Assessing the following factors may be useful in determining whether a patient is competent to provide an informed decision under the law:

- 1. Mental/psychological and cognitive disorders that could affect judgment: psychotic symptoms, clinical depression, dementia, substance abuse, PTSD, personality factors;
- Psychosocial factors: family dynamics and support systems (including caregiver issues), financial concerns, spiritual beliefs and values; community, cultural, ethnic, and religious factors; possible coercion by others; perceptions of being a burden to others;
- 3. Existential factors: sense of personal meaning and fulfillment in life, life values, what suffering means to the patient including but not limited to the suffering that results from physical pain; the patient's definition of a "good death" and, conversely, what would make life unbearable or not worth living;
- 4. Medical issues: the diagnosis and prognosis, organic/cognitive deficits, traumatic head injury history, dementia, delirium, side effects of medication, availability of adequate health care;
- 5. The patient's advance directives, living will, durable power of attorney for health care, POLST;

- 6. Palliative care, hospice, and alternative treatments/measures: the extent to which options such as withdrawing and withholding treatment, stopping eating and drinking, palliative sedation, etc., were identified, offered and/or tried; possible additional viable alternatives, and reasons why such alternatives were declined or not.
- 7. The patient's prior conversations about dying with family, friends, community, and members of the health care team.

#### 5. Depression

Depression or other affective, psychiatric, or cognitive symptoms and disorders can impair judgment and compromise the ability to make an informed decision. A common concern that is raised when a terminally ill patient requests life-ending medications is whether the patient is asking because he or she is clinically depressed. For psychologists, this involves two matters of particular concern.

The first is whether a finding of depression precludes the ability to make an informed decision. "Clinical depression, in and of itself, may not interfere with a person's ability to reason so much that it would lead to the individual being declared incapable of making health care decisions..." (Werth, 2001, p. 408). The question is whether clinical depression is impairing judgment to the extent that the person is unable to consider feasible alternatives to DWD or is making a decision that, while informed, is inconsistent with long-held values.

The second is that the actual diagnosis of depression in terminally ill patients is challenging. The Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> ed. (American Psychiatric Association, 2013) alone is inadequate for diagnosing depression in this patient population. For instance, somatic symptoms associated with depression in medically well populations, such as weakness, fatigue, change in appetite, sleep disturbance, changes in psychomotor functioning, and cognitive disturbances, are frequently present in seriously ill patients as a result of medications, paraneoplastic syndromes, the disease itself, or being terminally ill (Block & Billings, 1994; Van Loon, 1999). Block (2000) states that "evidence of hopelessness, helplessness, worthlessness, and guilt ... " are better indications of depression in people who are terminally ill than vegetative symptoms, while noting that these feelings, too, may be realistic in the context of the patient's physical condition. "However, when these symptoms are out of proportion to the patient's actual situation, they are useful indicators of major depression" (Block, 2000, p. 209). In addition, grief can mimic depression in dying patients. Grief and sadness are normal, expected reactions to facing terminal illness and death and thus must be differentiated from true clinical depression (Block, 2000, 2006; Cohen & Block, 2004).

Measures of depression may provide useful ways of exploring possible depression with the patient, but as discussed previously, psychologists are strongly urged not to rely solely on them to diagnose depression because norms have not been established for this specific population. Answers to questions on standardized instruments may be quite variable and may not reflect clinical depression or an impaired decision-making process. For example, when using the PHQ-9 as a screening tool, E. Goy (personal communication, March 19, 2009) suggests rephrasing the questions as follows:

What about feeling interest or pleasure in things? You may not be able to do all the things that used to give you pleasure, but do you still enjoy hearing, reading, or watching TV about those activities? Does anything give you a sense of excitement, enthusiasm, or interest? Are there other pleasures that you experience now, even though you are not as active?

In addition, Goy suggests that the examiner explain to the patient the reason for the question. She notes:

Sometimes I will even explain that we are trying to get at this core feature of depression, when people just totally lose their ability to react to ANYTHING with interest or pleasure. Once they understand why I am asking the question, they... usually can say quite reliably, "Oh, yes, I still get excited when my grandkids are coming to visit," or "that's it exactly; I just don't enjoy anything at all anymore."

Chochinov, Wilson, Enns, and Lander (1997) found that the question, "Have you been depressed most of the time for the past two weeks?" was sensitive and accurate in detecting a major depressive episode. This question could be further elaborated, as indicated above by Goy.

If standardized measures are chosen, the psychologist should be thoroughly familiar with scoring, norms, and limitations of these tests. There should be a clear rationale, given the extra burden on the dying patient. "The clinical interview is the gold standard for the diagnosis of depression" (Block, 2000, p. 210; see also Quill & Arnold, 2008a, b).

H. Leonard (personal communication, September 26, 2016) provides the following comments based on several years of experience evaluating patients requesting DWD in Washington State:

Although I go into an evaluation armed with questions, I have learned that it is such an emotional process, that a natural flow of conversation that covers many of the below topics is more humane than trying to follow a format. As I see it, the purpose of a DWD interview is to learn about someone's history in expressing a desire to have control over the end of their life, and to assess their ability to exhibit non-impaired psychological judgement about their request, while understanding the support and surrounding circumstances of their situation.... I am prepared to talk...in a conversational, rather than questioning, manner...

For further discussion, see <u>California's End of Life Options Act: CPA's Guidance for</u> <u>Psychologists</u> (2017, pp. 9–12).

### **E. Final Report and Recommendations**

The psychologist's evaluation will determine whether the patient is competent to make an informed decision and can go forward to use the law. Recommendations and conclusions reached in this process must be based on information from more than one source and supported by the data collected. Any limitations of measures used and of any data acquired through testing should be stated within the report. If the patient is not found competent, the psychologist should recommend what treatment, if any, might restore competence or recommend that the patient discuss palliative and end-of-life care options with his or her physician and health care team.

The <u>Washington State Department of Health Psychiatric/Psychological Consultant's</u> <u>Compliance Form</u> (Washington State Department of Health, 2016) required by Washington Department of Health is very brief. In addition to completing and submitting the form to the referring physician, the psychologist should maintain a written record of the evaluation. At a minimum, this written record should include the following:

- 1. The referral notes from the attending or consulting physician;
- 2. Signed consent from the patient indicating that the patient received an oral and written description of the procedures of the evaluation;
- 3. The written fee agreement;
- 4. Documentation of dates of service, nature of service and fees charged;
- 5. Appropriate signed authorizations for release of information from anyone who was interviewed as a collateral during the process;
- 6. Sources of data used;
- 7. All associated correspondence;
- 8. Notes taken during interviews with the patient and with all collaterals. If feasible, any narrative material from the collateral interviews that will be included in the report should be reviewed by the collaterals for accuracy;
- 9. Behavioral observations;
- 10. Psychological functioning, including any measures used and comments on findings;
- 11. Existential issues;
- 12. Psychosocial concerns;
- 13. Analysis of the four core functional abilities to make an informed consent:

- a. Understanding
- b. Appreciation
- c. Rational reasoning
- d. An enduring choice
- 14. Conclusions about capacity; presence or absence of coercion; and whether judgment has been impaired by psychiatric disorders.

# F. Summary

Evaluating the competence of a dying individual to make an informed decision regarding the use of the Washington State Death With Dignity law requires specialized skills, competencies, and self-reflection on the part of psychologists who engage in the evaluation process. Sensitive and methodical exploration of the complex nature of the patient's concerns is essential in formulating an accurate evaluation and providing appropriate recommendations for patients who wish to die with dignity.

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