

## BECOMING A “DEMENTIA-CAPABLE” ATTORNEY— REPRESENTING INDIVIDUALS WITH DEMENTIA

by James H. Pietsch<sup>1</sup>

### Introduction

As our nation’s older population continues to grow, so does the importance of having professionals in our society capable of responding to the unique needs of the elderly, including responding to the physical and mental effects of aging on this segment of the population.<sup>2</sup> These professionals should include those who are so-called “dementia-capable” professionals—individuals who are trained to recognize the signs of and address problems caused by Alzheimer’s Disease and related disorders or dementias (“ADRD”).<sup>3</sup> Over the next ten years, the number of individuals who will suffer from ADRD is expected to rise by 40 percent,<sup>4</sup> and the effects of ADRD can often be devastating on individuals, their families and society.<sup>5</sup> Age is the primary factor for developing

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<sup>2</sup> SANDRA L. COLBY AND JENNIFER M. ORTMAN, U.S. CENSUS BUREAU, PROJECTIONS OF THE SIZE AND COMPOSITION OF THE U.S. POPULATION: 2014 TO 2060, at 4 (Mar. 2015), available at <https://www.census.gov/content/dam/Census/library/publications/2015/demo/p25-1143.pdf> (“...the population is projected to age over the coming decades, with a higher proportion of the nation’s total population in the older ages (sixty-five and over).”)

<sup>3</sup> While this article will briefly discuss the terms dementia, dementia-capable and what the attributes of a dementia-capable attorney may be, there will be no suggestion that any one particular profession will be able to address the wide range of dementia-related problems presented by individuals with dementia. Rather the professional will be seeking to become capable of addressing the particular issues pertaining to the individual’s profession and will be familiar with basic concepts, referrals and issues faced by other professions working with individuals with dementia.

<sup>4</sup> ALZHEIMER’S ASS’N, 2015 ALZHEIMER’S DISEASE FACTS AND FIGURES 22 (2015), available at <http://www.alz.org/facts/overview.asp> [hereinafter 2015 ALZHEIMER’S FACTS AND FIGURES].

<sup>5</sup> ALZHEIMER’S ASS’N, GENERATION ALZHEIMER’S: THE DEFINING DISEASE OF THE BABY BOOMERS 4, available at [http://act.alz.org/site/DocServer/ALZ\\_BoomersReport.pdf?docID=521](http://act.alz.org/site/DocServer/ALZ_BoomersReport.pdf?docID=521) [hereinafter GENERATION ALZHEIMER’S].

dementia,<sup>6</sup> and with our aging population growing each year, it is more important than ever for those in the legal profession to become dementia-capable.<sup>7</sup>

The concept of dementia-capable professionals began percolating in the United States in reaction to the alarming prospects of ADRD.<sup>8</sup> Hawaii is at the forefront of addressing ADRD-related issues, and the State's community stakeholders have been active from the beginning.<sup>9</sup> Hawaii has also recognized the need to train legal and other services professionals regarding issues relating to dementia.<sup>10</sup> This article will provide an overview of the characteristics and challenges of attorneys striving to become "dementia-capable." This article will first provide a "bottom line up front" quick analysis of what it may mean to be a "dementia-capable attorney."<sup>11</sup> Please note that since there is an article in this volume detailing health care financing issues, this article will only provide an overview about the financing of health care including long-term care for individuals with ADRD. Practitioners and other readers should look to this article as a starting point on what it may take to become a dementia-capable attorney, but should not rely on it for legal advice or use it as a practice guide in any specific area of the law.

### **Bottom Line Up Front: Attributes of a Dementia-Capable Attorney<sup>12</sup>**

Bottom line up front, a dementia-capable attorney should be able to:

- Recognize the signs of dementia in a client or potential client and be professionally competent to address legal and practical issues as client capacity diminishes.
- Assess the capacity of clients suspected of having dementia and have an understanding of the varying legal capacity requirements for specific legal tasks such as executing wills, powers of attorney, trusts, contracts, and advance health care directives, etc.

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<sup>6</sup> NAT'L INST. OF NEUROLOGICAL DISORDERS AND STROKE, NAT'L INST. OF HEALTH, THE DEMENTIAS 1 (2013), available at [http://www.nia.nih.gov/sites/default/files/the\\_dementias\\_with\\_page\\_1\\_edit\\_5-22-14.pdf](http://www.nia.nih.gov/sites/default/files/the_dementias_with_page_1_edit_5-22-14.pdf) [hereinafter THE DEMENTIAS].

<sup>7</sup> The term "dementia-capable" in the title may provide some opportunity for humor in an otherwise somber discussion or, perhaps, confusion. It is not necessarily a term the author would use if challenged to come up with one. It may be too simple to use the term "Elder Law Attorney" but this emerging yet enduring field of practice may still be the best-suited *situs* for this category of attorneys skilled in addressing legal issues involving dementia.

<sup>8</sup> See generally GENERATION ALZHEIMER'S, *supra* note 5.

<sup>9</sup> See EXEC. OFFICE ON AGING, HAW. STATE DEP'T OF HEALTH, HAWAII 2025: STATE PLAN ON ALZHEIMER'S DISEASE & RELATED DEMENTIAS 2 (2013), available at [http://www.hawaiiadrc.org/Portals/\\_AgencySite/docs/ADRD\\_rev.pdf](http://www.hawaiiadrc.org/Portals/_AgencySite/docs/ADRD_rev.pdf) [hereinafter Hawaii 2025: State Plan on ADRD].

<sup>10</sup> See David M. Godfrey, *Developing Dementia-Friendly Communities and Dementia-Capable Professionals*, 36 BIFOCAL 61, at 79 (2015), available at [http://www.americanbar.org/publications/bifocal/vol\\_36/issue\\_3\\_february2015/dementia\\_friendly.html](http://www.americanbar.org/publications/bifocal/vol_36/issue_3_february2015/dementia_friendly.html)

<sup>11</sup> See "Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias" at [www.hawaiiadrc.org/site/439/resources.aspx](http://www.hawaiiadrc.org/site/439/resources.aspx) under Archived Publications and a mental exam at [www.aging.slu.edu/index.php?page=saint-louis-university-mental-status-slums-exam](http://www.aging.slu.edu/index.php?page=saint-louis-university-mental-status-slums-exam).

<sup>12</sup> The author's compilation based on reading and analyzing numerous resources cited in this article and experiences in working in the field of law, aging and medicine. Unanswered questions: Who determines the attributes? Who qualifies? Should there be a specialization certification? Is it really possible to have such an attorney or is it just aspirational?

- Have some core competency with dementia-related medical terms and in using cognitive assessment tools.
- Have some core competency in understanding mental health, substance abuse and domestic violence issues that may be exacerbated or precipitated by the underlying causes of dementia.
- Understand and use “dementia-friendly” communication skills.
- Work with other professionals, including doctors, nurses, social workers, clergy or spiritual advisors, financial planners, insurance agents, mediators and other attorneys with specialized legal skills.
- Know the national and local services available to help people with dementia and their caregivers and to help make appropriate referrals.
- Be aware of the ethical issues of representing a client with diminished capacity, multi-party representation, conflicts, confidentiality, and professional competence.
- Know the signs of elder abuse and financial exploitation and be able to protect clients from potential abuse, neglect and exploitation.
- Know how to create an advance health care plan that states who will make decisions and the duties involved, including planning tools for individuals without families or friends.
- Understand the ethical concepts of autonomy, self-determination as well as best interests and cultural influences.
- Know when to talk about Guardianship and Conservatorship if suitable alternatives are not set in place.
- Address the range of issues that can be impacted by dementia, by taking appropriate action before the full impact of ADRD sets in, in such important areas as:
  - Health care advance planning, advance directives and surrogate decision-making.
  - End-of-life decision-making including requests for life-prolonging treatment and requests for hastening death.
  - Hiring a caregiver, including contracts, labor law, insurance and taxes.
  - Driving a motor vehicle or utilizing other means of transportation.  
(Arranging other transportation when driving is no longer safe).
  - Financial, disability and long-term care advance planning, including direct deposit, joint accounts, automatic bill payment, powers of attorney, representative payee (and fiduciary) planning, money management services, guardianship, conservatorship and protective services.
  - Estate planning, including wills, living trusts, transfer on death trusts and accounts, taxes, probate, inheritance and beneficiary issues.
  - Private and public health care and long-term care benefits and payment options, including private pay, insurance, Medicare, Medicaid, and veteran benefits.
  - Other public, private and governmental benefits, including income, housing, nutrition, home care and personal care services.

### **Background**

Over the next several decades, the United States is projected to experience significant growth in its older/elderly population. According to the U.S. Census Bureau, one in five Americans

is projected to be age sixty-five and over by the year 2030.<sup>13</sup> This increase is largely due to the aging of the baby boomer generation, which consists of those who were born between 1946 and 1964.<sup>14</sup> In 2011, the baby boomers began turning sixty-five, and by 2030 they will all be age sixty-five and older.<sup>15</sup> By 2060, the number of persons ages sixty-five and over is projected to more than double, from 46 million to 98 million, representing a nine-point increase from fifteen percent in 2014 to twenty-four percent of the total U.S. population in 2060.<sup>16</sup>

People are living for longer periods, and can expect to live seventeen to nineteen more years once they reach the age of sixty-five.<sup>17</sup> As Americans continue not only to age but also to live for longer periods, the number of individuals needing services—including legal services—will increase.<sup>18</sup> Age is a known risk factor for developing dementia, and with the number of Americans age sixty-five or older doubling by 2060, so could the number of people with dementia.<sup>19</sup> America does not face an aging population alone. The world is aging as well.<sup>20</sup> By 2050, the world's older population will increase from 868 million in 2014 to more than two billion, which will be twenty-one percent of the world's population.<sup>21</sup> Furthermore, dementia is a global problem as well.<sup>22</sup> In 2013, there were 44.4 million people with dementia in the world; in 2030, that number will rise to 75.6 million and 135.5 million in 2050.<sup>23</sup> These numbers reflect a doubling of the number of people with dementia every twenty years.<sup>24</sup>

There are various forms of dementia disorders,<sup>25</sup> but by far the most common form of dementia in those over age sixty-five is Alzheimer's Disease.<sup>26</sup> According to the Alzheimer's Association, approximately 5.3 million Americans of all ages have Alzheimer's disease in 2015, but

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<sup>13</sup> ORTMAN, *supra* note 3, at 1.

<sup>14</sup> GRAYSON K. VINCENT & VICTORIA A. VELKOFF, U.S. CENSUS BUREAU, THE NEXT FOUR DECADES: THE OLDER POPULATION IN THE UNITED STATES 2010 TO 2050 at 1, (2010), *available at* <https://www.census.gov/prod/2010pubs/p25-1138.pdf>.

<sup>15</sup> ORTMAN, *supra* note 3, at 5 (The most significant increase is expected to occur between 2020 and 2030, “when then the population aged sixty-five and over is projected to increase by 18 million (from 56 million to 74 million).”).

<sup>16</sup> *Id.*

<sup>17</sup> Linda A. Jacobsen, et al., *America's Aging Population*, POPULATION BULLETIN 66, no.1 (2011) (“...men have a life expectancy of 17 years at age sixty-five, while women's life expectancy is 19.7 years...”) *available at* <http://www.prb.org/pdf11/aging-in-america.pdf>.

<sup>18</sup> See William E. Adams & Rebecca C. Morgan, *Representing the Client Who Is Older in the Law Office and in the Courtroom*, 2 ELDER L.J. 1, 2 (1994) (“The recognition of this impact on the legal profession is becoming evident as organizations are being formed for lawyers interested in practicing “elder law.”).

<sup>19</sup> See THE DEMENTIAS, *supra* note 6.

<sup>20</sup> AGE INTERNATIONAL, FACING FACTS: THE TRUTH ABOUT AGEING AND DEVELOPMENT (2015) *available at* <http://www.ageinternational.org.uk/olderworld>

<sup>21</sup> *Id.* at 7.

<sup>22</sup> Martin Prince, *Dementia is Global*, in FACING FACTS: THE TRUTH ABOUT AGEING AND DEVELOPMENT 44 (2015) *available at* <http://www.ageinternational.org.uk/olderworld>

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*

<sup>25</sup> ALZHEIMER'S ASSOCIATION, BASICS OF ALZHEIMER'S DISEASE 2-3 (2014) *available at* [https://www.alz.org/national/documents/brochure\\_basicsofalz\\_low.pdf](https://www.alz.org/national/documents/brochure_basicsofalz_low.pdf) [hereinafter Basics of Alzheimer's]; THE DEMENTIAS, *supra* note 6, at 3-11.

<sup>26</sup> *Id.*

5.1 million of those Americans are over the age of sixty-five.<sup>27</sup> “By 2050, the number of people age sixty-five and older with Alzheimer’s disease may nearly triple, from 5.1 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent or cure the disease.”<sup>28</sup> A diagnosis of Alzheimer’s Disease or a related disorder evidencing dementia most often raises important health care, legal, ethical, and social issues, including planning for an uncertain future. What is this disease? Put simply, “Alzheimer’s is a disease of the brain that causes problems with memory, thinking and behavior.”<sup>29</sup> It worsens over time and there is no cure for this devastating disease.<sup>30</sup>

On January 4, 2011, President Barack Obama signed into law the National Alzheimer’s Project Act (NAPA).<sup>31</sup> It requires the federal government to “create and maintain an integrated national plan (National Plan) to overcome Alzheimer’s disease” as well as coordinate research and services on the disease across all federal agencies.<sup>32</sup> The first National Plan was released in May of 2012.<sup>33</sup> In alignment with this national effort, the Hawaii State Department of Health’s Executive Office on Aging produced “Hawaii 2025: State Plan on Alzheimer’s Disease and Related Dementias” (Hawaii Plan).<sup>34</sup> The Hawaii Plan is “a blueprint created to greatly improve the way individuals with ADRD and their families will live in and be served by their communities.”<sup>35</sup> The plan gathers work from the Hawaii ADRD Task Force, caregivers and key informant surveys conducted in Hawaii and interviews from state experts and leaders, as well as recommendations from NAPA.<sup>36</sup> As part of the Hawaii Plan, a legal committee was formed to look at legal issues for the ADRD Task Force. It issued recommendations entitled “Legal, Ethical, Safety and Rights Issues for People Living with Memory Loss,” which became strategy 3D of the “ADRD Plan Draft with Action Steps.”<sup>37</sup>

The Hawaii Plan anticipates having “dementia-qualified” professionals who will work with other professionals trained or experienced with issues faced by individuals with dementia.<sup>38</sup>

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<sup>27</sup> 2015 ALZHEIMER’S FACTS AND FIGURES, *supra* note 4, at 16.

<sup>28</sup> *Id.* at 22.

<sup>29</sup> BASICS OF ALZHEIMER’S, *supra* note 24 at 1. *See also* NATIONAL INSTITUTE ON AGING, ALZHEIMER’S BASICS <http://www.nia.nih.gov/alzheimers/topics/alzheimers-basics> (click on “Alzheimer’s Information”) (last visited May 25, 2015).

“The disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and unpredictable behavior. After she died, he examined her brain and found many abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary tangles). Plaques and tangles in the brain are two of the main features of Alzheimer’s disease. The third is the loss of connections between nerve cells (neurons) in the brain.” *Id.*

<sup>30</sup> *Id.*

<sup>31</sup> National Alzheimer’s Project Act, Pub. L. No. 111-375, 124 Stat. 4100 (2011).

<sup>32</sup> U.S. DEP’T OF HEALTH AND HUMAN SERVICES, NATIONAL PLAN TO ADDRESS ALZHEIMER’S DISEASE: 2014 UPDATE, *available at* <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>.

<sup>33</sup> *Id.*

<sup>34</sup> [http://www.hawaiiadrc.org/Portals/\\_AgencySite/docs/ADRD\\_rev.pdf](http://www.hawaiiadrc.org/Portals/_AgencySite/docs/ADRD_rev.pdf)

<sup>35</sup> EXEC. OFFICE ON AGING, HAWAII STATE DEP’T OF HEALTH, HAWAII 2025: STATE PLAN ON ALZHEIMER’S DISEASE & RELATED DEMENTIAS EXECUTIVE SUMMARY (2013) *available at* [http://www.hawaiiadrc.org/Portals/\\_AgencySite/docs/ADRD.pdf](http://www.hawaiiadrc.org/Portals/_AgencySite/docs/ADRD.pdf).

<sup>36</sup> *Id.*

<sup>37</sup> *See* <http://www.hawaiiadrc.org/site/439/resources.aspx> for updates to the plan and for related publications on aging and disability. Copy of the report of the ADRD legal committee on file with the author.

<sup>38</sup> *Id.*

### **Dementia-Capable Attorneys**

At a basic level, dementia-capable attorneys should be able to work with other professionals in assisting clients and, as appropriate, caregivers or families, with assessing the current situation, planning for future physical and mental incapacity and setting in place appropriate courses of action to enhance client autonomy and to designate substitute decision-makers for use when needed. While they are not expected to become health care professionals, dementia-capable attorneys will need to have some basic knowledge about the medical factors impacting Alzheimer's disease and related diseases, which can lead to dementia.

For a dementia-capable attorney, it is a never-ending quest to maintain one's legal skills and to become comfortable in working with other professionals dealing with dementia-related issues, namely physicians, psychologists, nurses, social workers and case (or care) managers, plus clergy or spiritual advisors, financial planners, insurance agents, mediators and other attorneys with specialized legal skills, as necessary.

Some professionals specialize in serving older persons.<sup>39</sup> For example, geriatricians and geriatric psychiatrists are physicians who are board certified in serving the older population and can be quite useful in assisting with clients/patients who have been diagnosed with dementia. Likewise, Aging Life Care Professionals, also known as Geriatric Care Managers, specialize in assisting older persons, their families and caregivers in meeting long-term care arrangements. Aging Life Care Professionals generally have a background in gerontology, nursing, social work or counseling.<sup>40</sup> These are just some of the professionals with which a dementia-capable attorney should be familiar.

Planning ahead is important for a person with dementia who may still have sufficient residual decisional capacity to manage current financial, legal and personal matters and to express wishes for future decisions. Understanding the signs of dementia in a client or potential client can be the first step for an attorney who wishes to be dementia-capable.<sup>41</sup>

Dementia-capable attorneys may experience levels of complexity, satisfaction, frustration and even failure. Individuals with dementia may or may not be cooperative, no matter what their level of capacity may be. Legal, health care, financial and caregiving matters for dementia care-related issues can be complex. Often conflicts arise and a dementia-capable attorney should be able to sense when a situation can be handled by the attorney, when a situation may need to involve litigation and when mediation may be the best option. Mediation involving older persons, family members, neighbors, health care professionals and others is a growing field, including in Hawaii.<sup>42</sup>

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<sup>39</sup> See, e.g., American Geriatrics Society, <http://www.americangeriatrics.org/>

<sup>40</sup> AGING LIFE CARE ASS'N, <http://www.aginglifecare.org/> (follow "About Aging Life Care" tab and select "What you need to know.") ("An Aging Life Care Professional, also known as a geriatric care manager, is a health and human services specialist who acts as a guide and advocate for families who are caring for older relatives or disabled adults.")

<sup>41</sup> The Alzheimer's Association has identified ten warning signs of dementia: 1) Memory loss that disrupts daily life. 2) Challenges in planning or solving problems. 3) Difficulty completing familiar tasks at home, at work or at leisure. 4) Confusion with time or place. 5) Trouble understanding visual images and spatial relationships. 6) New problems with words in speaking or writing. 7) Misplacing things and losing the ability to retrace steps. 8) Decreased or poor judgment. 9) Withdrawal from work or social activities. 10) Changes in mood and personality. For the complete list with explanations, See ALZHEIMER'S ASSOCIATION, KNOW THE 10 SIGNS (2009) available at [http://www.alz.org/national/documents/checklist\\_10signs.pdf](http://www.alz.org/national/documents/checklist_10signs.pdf).

<sup>42</sup> The Mediation Center of the Pacific has established "Kupuna Pono," a program specifically designed for mediating elder issues. Some areas of mediation include disagreements over elder care, transitioning from

The challenge to lawyers and other professionals can be even more profound when issues relating to mental health, substance abuse, domestic violence, military service, and caregiving (or lack thereof) compound problems faced by an individual with dementia.<sup>43</sup> The individual may also have a history of being an abuser of the caregiver, partner, spouse, child or other family member. Some victims of abuse may or may not choose to stay or return to take on caregiving roles or help in other ways.<sup>44</sup> Attorneys can provide valuable counsel, advice and services for families and other caregivers for individuals who do not have the ability to comprehend, understand, or evaluate key legal and personal matters or to care for and to protect themselves, but, ethical issues abound.<sup>45</sup>

An appropriately coordinated plan can help eliminate uncertainty, provide for a decision-maker in the event of incapacity and provide guidance for families and caregivers. Knowledge about issues in this growing specialty area of legal practice can also help avoid or detect incidents of abuse, neglect and exploitation directed against individuals with dementia.

### **Dementia-Friendly Communication**

Dementia-capable professionals should be able to communicate effectively with clients in a manner that is professional, confident, honest and dignified. Borrowing from the first statement of its kind written by people with dementia on the subject of the Alzheimer's diagnosis experience provides an insider perspective on talking to persons with ADRD:

- Talk to me directly, the person with dementia. I am the person with the disease, and though those close to me will also be affected, I am the person who needs to know first.
- Tell the truth. Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
- Take my concerns seriously, regardless of my age.
- Deliver the news in plain but sensitive language. Please use language that I can understand and be sensitive to how this may make me feel.
- Give me tools for living with this disease.
- Work with me on a plan for healthy living.
- Recognize that I am an individual and the way I experience this disease is unique.
- Alzheimer's is a journey, not a destination.<sup>46</sup>

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medical discharge to home or assisted living, doctor-patient relationships and others. For more information about this program, visit <http://www.mediatehawaii.org/kupuna-pono>.

<sup>43</sup> See, e.g., AMERICAN PSYCHOLOGICAL ASSOCIATION, WHAT DO FAMILY CAREGIVERS DO? <http://www.apa.org/pi/about/publications/caregivers/faq/family.aspx> (follow "When the Care Recipient is Someone with a Mental Disorder") (last visited May 25, 2015) ("Guilt is an emotion often reported by . . . caregivers, and there is a growing need for education that a mental disorder is not related to or caused by family or parent behavior.").

<sup>44</sup> See, e.g., April D. Hill, *Bad Parents and Their Helper Children*, 26 NAELA NEWS 13 Dec.2014/Jan. 2015 available at [https://www.naela.org/NAELADocs/PDF/Library%20Tab/NAELA%20News/NAELANews\\_Vol26No6Linkd.pdf](https://www.naela.org/NAELADocs/PDF/Library%20Tab/NAELA%20News/NAELANews_Vol26No6Linkd.pdf).

<sup>45</sup> "Who is the Client?" becomes a major factor. See *infra* section on Ethical Issues.

<sup>46</sup> ALZHEIMER'S ASS'N, PRINCIPLES FOR A DIGNIFIED DIAGNOSIS (2014) available at [http://www.alz.org/national/documents/brochure\\_dignified\\_diagnosis.pdf](http://www.alz.org/national/documents/brochure_dignified_diagnosis.pdf).

Dementia-capable attorneys should be able to communicate with and work with other dementia-capable professionals in a dementia-capable service system.<sup>47</sup>

### Capacity Issues

Space may limit the topics addressed in this article but the topic of capacity (and incapacity) is key to start the discussion on legal issues relating to ADRD. Some practical issues arise not only in the determination of the capacity of a client but also in effectively memorializing conversations and other means of communication.

An essential trait of a dementia-capable attorney is to have, at minimum, a basic understanding of mental capacity/incapacity and competence/incompetence. When working with older clients or other clients suspected of having diminished capacity, it is imperative that an attorney remain aware of whether or not his/her client has the mental capacity to make informed decisions.<sup>48</sup> Not only can lack of mental capacity affect the client's daily living activities, safety, and ability to live independently, it can also impact the client's ability to execute valid legal documents and make personal health care decisions.

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<sup>47</sup> A model dementia-capable service system would:

1. Educate the public about brain health, including information on risk factors associated with developing dementia, first signs of cognitive problems, management of symptoms if individuals have dementia, support programs, and opportunities to participate in research.
2. Identify people with possible dementia and recommend that they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that might resemble it.
3. Ensure that program eligibility and resource allocation take into account the impact of cognitive disabilities.
4. Ensure that staff communicate effectively with people with dementia and their caregivers and provide services that:
  - a. Are person and family-centered
  - b. Offer self-direction of services
  - c. Are culturally appropriate
5. Educate workers to identify possible dementia, and understand the symptoms of dementia and appropriate services.
6. Implement quality assurance systems that measure how effectively providers serve people with dementia and their caregivers.
7. Encourage development of dementia-friendly communities, which include key parts of dementia-capability.

Jane Tilly et al., *Dementia-Capable States and Communities: the Basics*, ADMIN. FOR COMM. LIVING 4 (2014), available at [http://www.aoa.acl.gov/AoA\\_Programs/HPW/Alz\\_Grants/docs/DementiaCapabilityIssueBrief\\_09-22-14.pdf](http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/DementiaCapabilityIssueBrief_09-22-14.pdf).

<sup>48</sup> The first practical question for an attorney may very well be whether the potential client has the capacity to enter into a contract with the attorney, regardless of the general presumption that an adult is competent to do so. *See generally* 17B C.J.S. *Contracts* § 933 (2015).

“[T]he presumption that every adult who executes a contract is mentally competent to enter into a contract may be refuted by clear and convincing evidence that such a party was incapable of understanding the nature and consequences of his or her acts, or more exactly, that such party's mental powers had become so far affected as to make him or her incapable of understanding the character of the transaction in question.”

It should be noted that capacity and incapacity are sometimes used interchangeably with the terms competence and incompetence, but they should be distinguished.<sup>49</sup> The concept of capacity, or lack of capacity, is more activity specific than the concept of competency or incompetency.<sup>50</sup> Often it is helpful to simply ask, “Capacity for what?” For example, each specific activity that involves a decision, such as the provision of informed consent for medical treatment or the execution of a will, trust, advance directive, or power of attorney, may have a different required level of decisional capacity to be considered “valid.”<sup>51</sup>

As more is learned about mental function and greater attention is paid to preserving individuals' rights, greater emphasis is placed by professionals on identifying, in functional terms, specific mental tasks and skills people retain and lose.<sup>52</sup> Describing a person's ability or “capacity” to perform particular tasks, such as remembering to pay one's bills or calculating how much change one is owed, may be a more useful and meaningful way of looking at mental capacity.<sup>53</sup> It enables professionals to assess vulnerability more effectively and develop effective service plans. Understanding a client's mental capacity can help workers meet the vulnerable person's needs while avoiding unnecessary, restrictive, or intrusive interventions.

The premier resource for lawyers, judges and health care professionals with respect to capacity is a series of handbooks produced through a collaborative effort of members of the American Bar Association (“ABA”) and the American Psychological Association (“APA”).<sup>54</sup> According to its

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<sup>49</sup> Jennifer Moye et al., *Assessment of Capacity in an Aging Society*, 68 AM. PSYCHOL. 158 (2013) available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4160021/pdf/nihms620600.pdf>.

<sup>50</sup> Sabatino, *infra* note 56, at 485.

<sup>51</sup> Lawrence A. Frolik, “Sufficient” Capacity: The Contrasting Capacity Requirements for Different Documents, 2 NAELA J. 303, 316 (2006) (“[T]estamentary capacity does not include the more stringent requirement that the ‘person possesses sufficient mind to understand, in a reasonable manner,’ which reflects the Anglo-American legal tradition of demanding a higher degree of capacity to enter into a valid contract”).

<sup>52</sup> See, e.g., Marson et al., *Assessing Financial Capacity in Patients With Alzheimer Disease*, 57 ARCHIVES OF NEUROLOGY 877 (2004) (“As our society ages, clinical assessment of higher order functional capacities has become increasingly important. In areas like financial capacity, medical decision making capacity, medication compliance, and driving, society has a strong interest in accurately discriminating intact from impaired functioning.”).

<sup>53</sup> NAT’L COMM. FOR THE PREVENTION OF ELDER ABUSE, MENTAL CAPACITY, CONSENT AND UNDUE INFLUENCE, <http://www.preventelderabuse.org/elderabuse/issues/capacity.html> (last visited February 5, 2015) [hereinafter NCPEA Capacity].

<sup>54</sup> ABA Comm’n. on L. & Aging & Am. Psychological Ass’n, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers* (2005), available at <http://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf> [hereinafter Handbook for Lawyers]. This handbook was the first product of the ABA/APA Assessment of Capacity in Older Adults Project Working Group, established in 2003 under the auspices of the interdisciplinary Task Force on Facilitating APA/ABA Relations. This handbook offers a conceptual framework and practice tips for addressing problems of client capacity, in some cases with help from a clinician. The second product, *Judicial Determination of Capacity of Older Adults in Guardianship Proceedings: A Handbook for Judges* was published in 2006. This handbook overviews capacity determination, examines the role of judges, provides judges with a summary of the kinds of functioning assessed and suggests a 5-step model for assessment. Copies of both handbooks are available online at [www.apa.org/pi/aging](http://www.apa.org/pi/aging) and [www.abanet.org/aging](http://www.abanet.org/aging). *Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists* was published in 2008 and is available at <http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf>. “Formal collaborative efforts between the ABA and the APA began in 1995 with the establishment of the interdisciplinary Task Force on Facilitating APA/ABA Relations. Since that time, the task force has identified, developed, and pursued

executive summary, the specific goal of these handbooks is to review psychological assessment of six civil capacities of particular importance to older adults, namely, medical consent capacity, sexual consent capacity, financial capacity, testamentary capacity, capacity to drive, and capacity to live independently.

The handbooks also propose a number of ways that attorneys can promote and maintain client capacity. Some recommendations that the handbooks lay out focus on decisional abilities rather than cooperativeness or affability.<sup>55</sup> This helps to separate a client's possible decision-making relating to diminished capacity from her own personality style. In addition, the handbooks address the important topic of undue influence and introduce emerging areas of interest, such as the capacity to mediate, the capacity to participate in research, and the capacity to vote.<sup>56</sup>

Initially, of course, an attorney must be sure the client has sufficient capacity to participate in an attorney-client relationship and to provide true informed consent. Attorneys will make most of their own initial decisions about capacity. If they need help, attorneys can engage a health care professional usually in two ways:

- (1) Refer the client to a skilled health care professional who would analyze the client's mental health. Such health care professionals typically are medical doctors, psychologists, or advance practice nurses with special skills in capacity assessment. The health care professional, with the permission of the client/patient, could then determine what level of capacity the client has, whether it be for the making of a will or power of attorney.
- (2) Confer or consult using hypotheticals. Ask the health care professional whether the client has sufficient capacity based on observed behavior (my client presented with certain symptoms, etc.)<sup>57</sup>

Once the attorney is satisfied with the question of client capacity, the attorney must make sure to memorialize communications and case progress notes. Lawyers are required to explain legal matters to their clients adequately so that the clients may make informed decisions and, under most circumstances, lawyers are required to follow the instructions of their clients. There may be questions about the client's capacity, especially when the client's memory comes into question. As with healthcare professionals, the key to memorializing communications and case progression may be stated in three words, document, document, document.<sup>58</sup> Take copious notes of all meetings with the client so that it becomes part of the client's file. Be honest in taking notes and never alter a note after the fact. This article is not meant to review proper record-keeping practices but as with any legal case, a well-developed engagement letter and fee agreement (sometimes referred to as retainer agreement) can start the process. This memorializes the terms and conditions of hiring the attorney

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productive interdisciplinary projects and relationships. Interactions between the APA and the ABA have resulted in collaboration on a number of activities and facilitated useful forums for the exchange of views about critical issues and concerns affecting psychology and the law."

<sup>55</sup> See generally *id.*

<sup>56</sup> *Id.* at 16.

<sup>57</sup> See e.g., Charles P. Sabatino, *Representing a Client with Diminished Capacity: How do you Know it and What do you do about it*, 16 J. AM. ACAD. MATRIMONIAL L. 481 (1999-2000); Charles P. Sabatino and Erica Wood, *The Conceptualization of Legal Capacity of Older Persons in Western Law*, BEYOND ELDER LAW 35 (2012); See also *supra* note 53 for a discussion on the three ABA-APA handbooks for lawyers, psychologists and judges.

<sup>58</sup> See, e.g., AM. PSYCHOLOGICAL ASS'N, RECORD KEEPING GUIDELINES, <http://www.apa.org/practice/guidelines/record-keeping.aspx> (providing guidelines for psychologists which are also very useful for attorneys who are assisting clients with capacity issues) (last visited May 25, 2015).

and sets forth the exact duties of the law firm, the attorney and the client. The document is directed to the client and is signed by both the attorney and the client and is usually created after the initial conference with the client. It will identify the nature of the problem or representation and will set the parameters of the attorney-client relationship. An original copy is retained in the client's file, which will continue to be the repository for client information, communications, consultations, powers of attorney and other materials. In addition, the basic client file should include:

- Client identifying information and first contact information.
- Relevant case history and risk factors, medical status and attempts to get prior treatment records.
- Dates of legal services and fees.
- Records of diagnostic impressions, assessments, treatment plans, consultations, summaries and testing reports and supporting data for capacity issues.
- "Informed-consent" documentation, consent to audiotape or videotape,<sup>59</sup> and release of information documentation.
- Relevant telephone calls and out-of-office contacts.
- Follow-up efforts when clients do not respond to letters or other means of communication.

### **Things to Consider if Diminished Capacity is Suspected**

A decline in mental capacity is normal and not necessarily a result of disease.<sup>60</sup> As we age, "normal cognitive aging" means that multiple cognitive abilities decline over time, including, short-term memory, brain processing speed, executive/planning abilities, "fluid" intelligence, numeracy and arithmetic skills.<sup>61</sup> On the positive side, there may even be some age related cognitive improvement, including experience and pattern recognition and even "wisdom."<sup>62</sup> As such it is important not to jump to conclusions that age or occasional forgetfulness is indicative of dementia.

There is usually a difference between memory loss and "dementia," which is a term many people fear. In order to address stigmatization, the American Psychiatric Association is reducing the use of the term "dementia" in favor of major or minor neurocognitive disorder.<sup>63</sup> This article will

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<sup>59</sup> Video recordings can in some cases be helpful, since the recording allows a client or testator to explain that he or she is executing a will voluntarily. *See, e.g.,* Gerry W. Beyer, *Will Contests - Prediction and Prevention*, 4 EST. PLAN. & COMMUNITY PROP. L.J. 1, 24 (2011) ("The mere existence of the video recordings reduces litigation because potential will contestants are reluctant to proceed in the face of the strong evidence the recording provides."). Video recordings can also work against the client. A client may appear more confused or incapacitated on a recording than in person. In *Seagraves v. Seagraves*, 206 N.C. App. 333, 698 S.E.2d 155 (2010), the testator was recorded during a will execution. Unfortunately, the video showed "a very confused 90 year old woman who is barely able to respond to her attorney's leading questions and who is not even aware how she is devising her estate." *Id.*

<sup>60</sup> ALZHEIMER'S DRUG DISCOVERY FOUND., THE DIFFERENCE BETWEEN ALZHEIMER'S DISEASE AND NORMAL COGNITIVE AGING, <https://www.alzdiscovery.org/news-room/view/the-difference-between-alzheimers-disease-and-normal-cognitive-aging> (last visited May 25, 2015).

<sup>61</sup> *See id.*

<sup>62</sup> Daniel Marson, fellow and past president of the Nat'l Academy of Neuropsychology, Co-Presenter at the Dementia Training for Lawyers seminar at The Queen's Conference Center in Honolulu (Feb. 2, 2015).

<sup>63</sup> James Siberski, *Dementia and DSM-5: Changes, Cost, and Confusion*, 5 AGING WELL 12 (2012) ("It was believed that the word dementia was stigmatizing toward older individuals and not well accepted by younger

continue to use the term “dementia,” however, to describe both moderate and major neurocognitive disorders.<sup>64</sup>

An individual can have short-term memory loss but not have dementia. For example, asking where one may have put one’s keys may have nothing to do with dementia, but simply a brief lapse in short-term memory. Notably, dementia is a term that applies to a medical disorder, which may be evidenced by symptoms of damage or disease to the brain’s cognitive function.<sup>65</sup> Dementia may be reversible or irreversible and progressive.<sup>66</sup> A person with dementia may suffer from short-term or long-term memory loss, confusion or disorientation or may lose the ability to problem-solve or to complete multi-step activities. Sometimes dementia can affect a person’s personality, behavior or attention span.<sup>67</sup>

Before an individual reaches the point of having dementia, there may be a period of time in which an individual may be experiencing moderate or mild cognitive impairment (“MCI”).<sup>68</sup> An individual with MCI may still have substantial ability to pursue appropriate legal, financial and personal planning for future incapacity.<sup>69</sup> This is also the area best suited for a dementia-capable attorney to provide essential counsel, advice and document preparation to enhance, preserve or continue an individual’s autonomy and self-determination and to set into place decision-makers with stand-by authority to act on behalf of the client when needed. The diagnosis of MCI may prove valuable to the patient for legal/financial issues, especially if the health care provider is trained to make suggestions to patients to seek legal advice on planning for the future.<sup>70</sup>

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individuals with HIV dementia. The new term focuses on the decline from a previous level of functioning as opposed to a deficit.”) (Aging Well Magazine was rebranded in 2013 as “Today’s Geriatric Medicine.”)

<sup>64</sup> For more information about the classification of mental disorders such as dementia, *See* AMERICAN PSYCHIATRIC ASSOCIATION, THE DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, 5th ed. (2013), available at <http://www.psychiatry.org/practice/dsm>.

<sup>65</sup> THE DEMENTIAS, *supra* note 6, at 2.

<sup>66</sup> *Id.* at 3.

<sup>67</sup> *Id.* at 2.

<sup>68</sup> Am. Psychological Ass’n, *Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change*, 67 AM.PSYCHOLOGIST 1 at 2 (2012) available at <http://www.apa.org/practice/guidelines/dementia-age.pdf> (“Some older adults have memory and cognitive difficulties that are greater than those typical of normal aging but not so severe as to warrant a diagnosis of dementia.”)

<sup>69</sup> Ronald C. Petersen, *Early Diagnosis of Alzheimer’s Disease: Is MCI Too Late?* in 6 CURR ALZHEIMER RES. 324 (2009) available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3098139/pdf/nihms198364.pdf> (“The field of aging and dementia research is advancing rapidly toward the stage of earlier identification . . . [T]he construct of mild cognitive impairment (MCI) has come to represent an intermediate clinical state between the cognitive changes of aging and the very earliest features of Alzheimer’s disease.”).

<sup>70</sup> Presentation regarding diagnosis of MCI by Ahmed, Iqbal Access to Justice Conference June 19, 2015. A diagnosis of MCI involves:

A. Evidence of modest cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, perceptual motor, or social cognition) based on:

1. Concern of the individual, a knowledgeable informant, or the clinician, that there has been a mild decline in cognitive function; and
2. A modest impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment.

A lawyer should take advantage of a client's ability to make decisions at the early stages of diminished capacity by having the client portray exact wishes to the lawyer. Thereafter, if the problem worsens, at least the lawyer will have a better understanding of what the client's wishes are and how to protect the client's interests. The ethical issues in protecting a client under disability will be discussed later in this article.

Lawyers should be aware of ageist stereotypes and consider whether mitigating factors could explain unusual or changed behavior. It is important for a lawyer not to let ageist stereotypes cloud his or her judgment in assessing a client's ability to make decisions. Awareness of extenuating circumstances, such as a client's poor mood on a particular day, can help in assessing a client's capacity. Checking with the client on a regular basis can help the lawyer establish some kind of baseline as to his or her client's decision-making capacity. Needless to say, compassion, caring, empathy and patience are traits that can be helpful to attorneys who are dealing with the sometimes overwhelming emotional and practical issues confronted by individuals with dementia and their caregivers and families.

By becoming familiar with these broad factors, a lawyer can be more attuned to specific categories, such as cognitive factors, emotional factors, and behavioral factors.<sup>71</sup> Cognitive factors include memory loss, and communication and comprehension problems, among others. If a client quickly forgets information discussed in the interview or can remember things or events that happened years ago, but not things a couple of days ago, this can be a sign that the client has a diminished capacity. This could be an opportunity for the lawyer to take protective measures to help the client remember.

The previously mentioned ABA/APA legal handbook mentions that attorneys can "break the ice" in communicating with the client by mentioning things like the weather and sports.<sup>72</sup> This strategy can help the attorney create a relationship with the client where the client and the attorney develop trust in one another. Asking such questions can also give the attorney a better sense of how the client would respond to questions that are more pertinent to representation. For example, if the client has a difficult time responding to a question such as the current weather, it may be an indication of potential difficulties in future conversations about more difficult legal subjects.<sup>73</sup>

It is also important to interview the client alone.<sup>74</sup> This strategy ensures confidentiality and trust.<sup>75</sup> Following such a protocol is very important because, at times, the person bringing the client to the attorney may want to speak on the client's behalf. Despite the third party's intentions, the lawyer's priority is the client and that is to whom the lawyer owes a duty.<sup>76</sup> This is important for any profession, not just lawyers, and other professionals also need to be mindful that their duty is to the

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B. The cognitive deficits do not interfere with capacity for independence in everyday activities (complex instrumental activities of daily living such as paying bills or managing medications are preserved, but greater effort, compensatory strategies, or accommodation may be required).

C. The cognitive deficits do not occur exclusively in the context of a delirium.

D. The cognitive deficits are not better explained by another mental disorder (e.g., major depressive disorder, schizophrenia).

<sup>71</sup> See note 54 *infra Handbook for Lawyers*.

<sup>72</sup> *Id.* at 36.

<sup>73</sup> *Id.*

<sup>74</sup> Roberta K. Flowers, *To Speak or Not to Speak: Effect of Third Party Presence on Attorney Client Privilege*, 2 NAELA J., 153 at 169 (2006).

<sup>75</sup> *Id.*

<sup>76</sup> *Id.*

client. Even though it might be easier and more convenient to talk to the person who has accompanied the client, this does not satisfy the lawyer's professional obligation to the client.

Attorneys can also help promote capacity by encouraging client participation.<sup>77</sup> Sometimes, it may be the case that a client is accustomed to having people speak on his or her own behalf and, thus, the client does not take advantage of the opportunity to participate in his or her own affairs. By having the client participate, it not only makes the client aware that he or she is being valued and heard but also provides some feedback that confirms or disaffirms what is being talked about.

As more professionals (including attorneys, physicians, psychologists, nurses and case managers) attempt to work with individuals or families of individuals who are totally, partially, or intermittently mentally incapacitated, it becomes clear that not only is it often difficult to determine what the best course of action might be, but it is also difficult to fulfill the ethical requirements of the professional-client/patient relationship. A variety of client capacity screening tests have been used in the health care field over the years and a few are discussed in the following section.<sup>78</sup>

### **Determining Capacity**

While it may be tempting for lawyers to employ some of the following tests, it may be best to resist the urge and rely on professional evaluations since using and interpreting such tests are not necessarily simple tasks. In addition to physicians (including psychiatrists), psychologists are trained to assess capacity. Psychiatrists are medical doctors who have taken many years of additional training in mental, emotional, and behavioral disorders. Psychologists, while not medical doctors, hold advanced degrees in the study of mind and behavior in relation to a particular field of knowledge or activity. Psychiatrists and psychologist are often called on to provide treatment or therapy to patients as well as to test individuals for mental, emotional, and behavioral problems and for mental capacity. Issues relating to potential costs to determine capacity also need to be addressed by the attorney and the client. Often fees for treatment and therapy are covered by insurance, but "forensic work" relating to legal issues may not be covered. A person's attending physician, psychiatrist, or psychologist may also bring in other professionals (such as a speech therapist) to assess a difficult case.

The "Clock Drawing Test" is one method that has been used as a brief cognitive screen by professionals skilled in the field of mental functioning, for individuals with questionable competency.<sup>79</sup> The test starts out by requesting a client to "draw a clock and put in all the numbers." The client is then asked to "set the time at a quarter to seven" or some other time. Points are given for accomplishing certain instructions in a certain way.

The Mini-Mental State Exam (MMSE) is often used to determine a person's mental status.<sup>80</sup> It is a classic test developed in 1975 that is still used to quickly determine a person's ability to recall, compute, comprehend and solve visual problems.<sup>81</sup> It is not always accurate and it is not meant to

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<sup>77</sup> MODEL RULES OF PROF'L CONDUCT R 1.14 cmt. 1, (2014).

<sup>78</sup> Breda Cullen et al., *A review of screening tests for cognitive impairment*, 78 J. NEUROLOGY, NEUROSURGERY & PSYCHIATRY 790 (2007), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC211774/>.

<sup>79</sup> See G.P. Wolf-Klein et al., *Screening for Alzheimer's Disease by clock drawing*, 37 J. AM. GERIATRIC SOC'Y 730 (1989).

<sup>80</sup> Marshal Folstein et al., "*Mini-Mental State*" a Practical Method for Grading the Cognitive State of Patients for the Clinician, 12 J. PSYCHIATRIC RES. 189 (1975).

<sup>81</sup> The MMSE consists of 11 simple questions or tasks grouped into 7 cognitive domains. A possible score of 30 is used to provide a picture of an individual's present cognitive performance based on direct observation of completion of test items/tasks.

be used by lay persons. Lawyers might find it helpful to review the MMSE or to take it as an exercise in determining “capacity” in the medical sense or “competence” in the legal sense.

Since the MMSE is subject to a fee,<sup>82</sup> more and more professionals are looking at other cognitive tests, including the Montreal Cognitive Assessment or MoCA®.<sup>83</sup> The instructions for the test indicate that the test may be administered by anyone who understands and follows the instructions, but only a health professional with expertise in the cognitive field may interpret the results.<sup>84</sup>

The Saint Louis University Mental Status (“SLUMS”) Examination is gaining popularity in the United States. Saint Louis University researchers compared the SLUMS and the MMSE on 705 men who were treated at the Veterans Administration Hospital in St. Louis in 2003. They found that while both tools detected dementia, the authors believed that the SLUMS is possibly better at detecting mild neurocognitive disorder, which the MMSE failed to detect, but they indicated that it needs to be further investigated.<sup>85</sup> Since it only takes about seven minutes to administer the SLUMS and since there are no restrictions on its use, it is becoming an essential tool for use by many health care professionals working with individuals who may be facing cognitive difficulties.

### **Effects of a Determination of Incapacity**

A determination of legal incapacity can have a dramatic and long-lasting effect on a person’s life and should be supported by evidence of functional impairment over time. Age, eccentricity, poverty or medical diagnosis alone should not be considered sufficient to justify a finding of incapacity. State laws provide thresholds for determining incapacity for purposes of guardianship or conservatorship.<sup>86</sup>

If a person is deemed to be “incompetent” in one area, he or she may not necessarily need total intervention or assistance to function in another area. The person may need only a little help, guidance, or persuasion. On the other hand, he or she may be able to adjust his or her own style of living and may not need any help at all.

There are many issues that arise once a person is deemed to lack capacity, including entering into contracts, such as those with accountants, brokers, hired caregivers and other service providers.

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<sup>82</sup> John C. Newman, *Copyright and Open Access at the Bedside*, 365 NEW ENGLAND J. OF MED. 2447 (2011), available at <http://www.nejm.org/doi/full/10.1056/NEJMp1110652>. (In 2001, the authors of MMSE granted a worldwide exclusive license to Psychological Assessment Resources, a publisher of psychological assessment materials, to publish, distribute and manage their intellectual property rights. The MMSE may be purchased from PAR ([www4.parinc.com](http://www4.parinc.com)) for \$1.23.).

<sup>83</sup> Montreal Cognitive Assessment (MoCA®), Copyright© Dr. Ziad Nasreddine 2003 to 2015, <http://www.mocatest.org/>. According to the website, “(t)he test may be administered by anyone who understands and follows the instructions, but only a health professional with expertise in the cognitive field may interpret the results. The test should be made available free of charge to patients and Written permission and Licensing Agreement is required if funded by commercial entity or pharma.”

<sup>84</sup> *Id.*

<sup>85</sup> See, SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. *Am J Geriatr Psychiatry*. 2006 Nov;14(11):900-10.

<sup>86</sup> See, e.g., HAW. REV. STAT. § 560:5-102 (2014). “Incapacitated person” means an individual who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate and reasonably available technological assistance.

When an individual has been diagnosed with a form of dementia and has sought the assistance of an attorney, the attorney will usually start the planning process, including planning for increasing mental incapacity and, ultimately, death. A few brief planning-tool examples follow. A more detailed analysis will need to wait for future articles on this subject but, as indicated earlier in this article, most topics revolve around the question, “Capacity for what?”

A client with dementia may be inclined (or persuaded) to consider an estate plan. As to testamentary capacity, questions may arise whether an individual has the ability to make a will. The threshold is rather low, “An individual eighteen or more years of age who is of sound mind may make a will.”<sup>87</sup> The presumption of law is in favor of testamentary capacity and anyone who insists on the contrary has the burden of proof, except where insanity in the testator has been shown to exist at a time prior to the execution of the will. In that event, the proponent must show that it was executed at a lucid interval.<sup>88</sup>

Powers of attorney can be very effective legal tools in planning for incapacity. Determining capacity with respect to execution of a power of attorney or with respect to effectiveness or ineffectiveness during periods of incapacity is essential and the threshold is higher than that to execute a will.<sup>89</sup>

As to capacity to make health care decisions, including medical treatment and end-of-life decisions, definitions vary among the states, but as an example under Hawaii law, (Uniform Health Care Decisions Act (Modified) or (“UHCDCA”), “Capacity means the individual’s ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.”<sup>90</sup> The definition of health care under this law is expansive but does not specifically mention research or experimental procedures,<sup>91</sup> which is a related issue for health care providers.<sup>92</sup>

For the individual patient, having access to experimental medicines may be important.<sup>93</sup> A significant number of healthcare providers are involved in research activities with their patients or individuals who are not their patients. For example, research into areas such as Alzheimer’s Disease is especially in the forefront of science.<sup>94</sup> The attorney will need to know the process for obtaining consent from guardians, surrogates or courts as the situation may dictate. This topic will be expanded in a section entitled “Research Issues.”

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<sup>87</sup> HAW. REV. STAT. § 560:2-501 (2013).

<sup>88</sup> *In re Estate of Herbert*, 90 Haw. 443, 455, 979, P.2d 32, 51 (1999). “Testamentary capacity has been defined as the ability to know: (1) the nature and extent of the testator or testatrix’s estate; (2) the identity of the beneficiaries and their relationship, whether by blood or other circumstances, to the testator or testatrix (*i.e.*, the objects of his or her bounty); (3) the disposition that the testator or testatrix is making; and (4) how these elements relate so as to form a rational and orderly plan for the disposition of the testator or testatrix’s estate.”

<sup>89</sup> See, e.g., HAW. REV. STAT. § 551E-1 (2014) (“Incapacitated” or “incapacity” means the inability of an individual to manage property or business affairs because the individual. . . (1) Has an impairment in the ability to receive and evaluate information or make or communicate decisions even with the use of technological assistance).

<sup>90</sup> HAW. REV. STAT. § 327E(2) (2014).

<sup>91</sup> *See id.*

<sup>92</sup> *Handbook for Lawyers*, *supra* note 54, at 19.

<sup>93</sup> Sheng Chen, Current Experimental Therapy for Alzheimer’s Disease, 5 CURR. NEUROPHARMACOL. 127 (2007) available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2435347/>.

<sup>94</sup> ALZHEIMER’S ASS’N, RESEARCH CENTER, <http://www.alz.org/research/> (last visited 5/25/2015).

Another topic that cannot be addressed in full in this article but certainly can involve the attorney, the client, the physician, the family and even the police, is driving. While some drivers with dementia adjust their driving habits or stop driving altogether based on their own judgment or family urging, others continue to drive for as long as possible.<sup>95</sup>

### **Incapacity, Undue Influence, and Abuse**

As to capacity to protect one's self, the concepts of undue influence and mental capacity are often joined. The Hawaii Adult Protective Service ("APS") law defines capacity as, "...the ability to understand and appreciate the nature and consequences of making decisions concerning one's person or to communicate such decisions."<sup>96</sup> Screening for specific capacities with respect to abuse, neglect or exploitation may be required.<sup>97</sup> Undue influence refers to questions as to whether the individual is acting freely and knows what he or she is doing. Undue influence is often seen in questions relating to contracts,<sup>98</sup> but is also seen as a process or method used to commit financial or sexual exploitation through manipulation or deceit. For example, perpetrators use various techniques and manipulations to gain power and compliance, exploiting the trust, dependency and fear of older adults. Over time, the perpetrators gain control over the decision making of their unwitting victims.

Inducing someone to sign a legal document or give a gift, for example, may constitute abuse if the person does not fully understand the transaction, appreciate the value of what they are giving away, or comprehend the implications of what they are doing. Some of the first questions often

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<sup>95</sup> See Charles G. Warner, *Driving and Dementia*, ALZHEIMER'S ASS'N, N. CAL. & N. NEV. CHAPTER BLOG (Apr. 30, 2014) <http://www.alzheimersblog.org/2014/04/30/driving-dementia/comment-page-1/>. One Hawaii law aimed at addressing unsafe driving requires drivers age seventy-two and above to renew their driver's license every two years, however, it does not mandate a physician to report impaired elderly drivers to the DMV. Haw. Rev. Stat. §286-106(2) (2012) ("The license shall expire on the first birthday of the licensee occurring not less than two years after the date of the issuance of the license, if, at that time, the licensee is seventy-two years of age or older"). Hawaii physicians encounter an ethical dilemma from their duties embodied in the AMA Code and federal and Hawaii statutes. The American Medical Association ("AMA") Code advises physicians to assess their patients' impairments that may affect their driving ability. The code indicates that it is "desirable and ethical to notify the Department of Motor Vehicles" in situations where the patient's driving impairment implies a strong threat to patient and public safety. It indicates that physicians should disclose and explain to their patients this responsibility to report. But the AMA Code also recognizes that the physician's role in reporting to the DMV is dictated by his or her state's mandatory reporting laws. A. Med. Ass'n., Code of Medical Ethics of the American Medical Association, Ethical Opinion 2.24 – Impaired Drivers and Their Physicians (2000). <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion224.page?>

<sup>96</sup> HAW. REV. STAT. § 346-222 (2014).

<sup>97</sup> The University of Alabama at Birmingham ("UAB") "Brief Financial Capacity Screen" ("BFCS") was developed by Daniel Marson, JD, PhD., specifically for APS workers in Georgia to use (agencies involved were the Georgia Alzheimer's Association and Georgia Division of Aging Services). There are two attachments that comprise the BFCS: a clinical interview screen and an optional direct assessment module (where APS workers can directly test certain client financial abilities). There are also administration manuals linked to this measure, which are available to APS workers. UAB retains all the intellectual property rights in this measure. As more professionals and agencies become "dementia-capable," such screens may become more common. For example, the Hawaii Department of Human Services could incorporate such a screen in its Adult Protective Services program.

<sup>98</sup> RESTATEMENT (SECOND) OF CONTRACTS § 177 (1981). "Undue influence is unfair persuasion of a party who is under the domination of the person exercising the persuasion or who by virtue of the relation between them is justified in assuming that that person will not act in a manner inconsistent with his welfare."

raised is “Did this person understand what he or she was doing when he or she gave a gift or transferred property? Was coercion, trickery, or undue influence employed?”

Undue influence may exist without mental impairment; and mental impairment may exist without undue influence. People are more vulnerable to manipulation when they have certain psychological or medical conditions, however, such as dementia. Both address the issue of vulnerability. If a person takes advantage of an elder’s vulnerability to obtain assets, the act can be prosecuted as a crime.<sup>99</sup>

The APS law in Hawaii, which will be addressed later in this article, also points out that exploiting a vulnerable adult through undue influence may constitute abuse under the law.<sup>100</sup> Clarifying these issues is critical for individuals who are mandated or who wish to report suspected elder abuse and for professions and disciplines that collaborate with APS. While the APS law refers to vulnerable adults, anyone can be unduly influenced, including the stressed, ill, sleep deprived, lonely or frightened of any age, but the elderly appear to be more vulnerable. Undue influence can also occur when a person is making a will. For example, in *In the Matter of the Estate of Herbert*, the Hawaii Supreme Court held that Carmen Herbert, who died at the age of eighty-five, had been unduly influenced when she executed her third and final will. The will was therefore denied probate.<sup>101</sup>

Individuals with dementia may be more susceptible to abuse, neglect, and exploitation. According to a report sponsored by the Department of Justice, The Elder Justice Roadmap, about half of people with dementia may suffer from abuse or neglect by their caregivers and cognitive impairment reduces financial capacity, increasing risk of financial exploitation.<sup>102</sup>

Since most individuals who suffer from dementia are age sixty-five and older, the laws, policies, procedures and structures established to protect older persons from abuse, neglect, and exploitation can often be used to protect individuals with dementia. Elder law justice organizations and elder law agency websites often have lists of tips to aid older Americans in protecting their finances and keeping vigilant against would-be abusers. These tips also can apply to individuals with dementia, without regard to age. For example, the National Committee for the Prevention of Elder Abuse’s website lists risk factors that increase the susceptibility of an older person to exploitation.<sup>103</sup> The list includes isolation, loneliness, recent losses, physical or mental disabilities, lack of familiarity with financial matters, and having family members who are unemployed and/or have substance abuse problems.<sup>104</sup>

Likewise, *Clinical Geriatrics Magazine* lists factors predisposing one to financial exploitation.<sup>105</sup> Their list includes advanced age (75 years old or more), being unmarried, widowed,

<sup>99</sup> See HAW. REV. STAT. § 706-662 (2014).

<sup>100</sup> HAW. REV. STAT. § 346-222 (2014) (“Financial exploitation may be accomplished through coercion, manipulation, threats, intimidation, misrepresentation, or exertion of undue influence.”).

<sup>101</sup> *In re Estate of Herbert*, 90 Haw. 443, 979 P.2d 39 (1999), as amended on denial of reconsideration (Apr. 15, 1999).

<sup>102</sup> See U.S. DEP’T OF JUSTICE, DEP’T OF HEALTH & HUMAN SERVS., THE ELDER JUSTICE ROADMAP (2014), available at [http://www.ncea.acl.gov/Library/Gov\\_Report/docs/EJRP\\_Roadmap.pdf](http://www.ncea.acl.gov/Library/Gov_Report/docs/EJRP_Roadmap.pdf).

<sup>103</sup> See FINANCIAL ABUSE, NAT’L COMM. FOR THE PREVENTION OF ELDER ABUSE [http://preventelderabuse.org/elderabuse/fin\\_abuse.html](http://preventelderabuse.org/elderabuse/fin_abuse.html) (last visited May 25, 2015) [hereinafter Financial Abuse].

<sup>104</sup> *Id.*

<sup>105</sup> See Ryan C. W. Hall et al., *Exploitation of the Elderly: Undue Influence as a Form of Elder Abuse*, 13 CLINICAL GERIATRICS 28, 30 (2005).

or divorced, organic brain damage, cognitive impairment, depression, dependence on abuser, being estranged from children, frailty, taking multiple medications, and fearing a change of living situation.<sup>106</sup> By consulting lists like these and identifying when such risk factors are present, families, friends, and others concerned about older persons can watch for signs of abuse and protect against it.

Other indicators include withdrawals or transfers from bank accounts that the older person cannot explain; new “best friends”; legal documents that the older person did not understand at the time he or she signed them; a caregiver expressing excessive interest in the money being spent on the older person, missing belongings or property; absence of documentation about financial arrangements; and suspicious signatures on checks and other documents.<sup>107</sup> *Clinical Geriatrics Magazine* lists characteristics of exploiters of the elderly, including developing a caregiving role, instilling a sense of helplessness and dependency, isolating the elderly person from family members and other social contacts, enhancing inadequacy and diminished self-worth in the victim, falsifying credentials, and having a predatory nature.<sup>108</sup> Communities can guard against elder abuse by using these characteristics to identify potential exploiters and by recognizing indicators of exploitation early so that it can be stopped before significant harm is done.

According to the ABA Commission on Law and Aging,<sup>109</sup> although there is no overall federal law on elder abuse, all 50 states, the District of Columbia, Guam, Puerto Rico, and the Virgin Islands have enacted some form of legislation providing for adult protective services. These laws generally also apply to individuals with dementia since, in most states, these laws apply to abused adults who have a disability, vulnerability, or physical or mental impairment. Some states have specific elder protective services laws or programs;<sup>110</sup> other states, like Hawaii, do not have such programs, although there are many laws and interventions that can provide protection of older adults.<sup>111</sup>

### **Hawaii’s Adult Protective Services Law**

Dementia-capable attorneys need to know at least the basics of Hawaii’s Adult Protective Services statute. Individuals with dementia may fit one or more criteria for protection. The law does not make specific provisions based on age although it does mention the elderly as an important segment of the population deserving protection.<sup>112</sup> The statute uses the term “vulnerable adult,”

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<sup>106</sup> *See id.*

<sup>107</sup> *See* FINANCIAL ABUSE, NAT’L COMM. FOR THE PREVENTION OF ELDER ABUSE [http://preventelderabuse.org/elderabuse/fin\\_abuse.html](http://preventelderabuse.org/elderabuse/fin_abuse.html) (last visited May 25, 2015) [hereinafter Financial Abuse].

<sup>108</sup> *See* Ryan C. W. Hall et al., *Exploitation of the Elderly: Undue Influence as a Form of Elder Abuse*, 13 CLINICAL GERIATRICS 28, 30 (2005).

<sup>109</sup> *See* ABA COMM’N ON LAW & AGING, <http://www.abanet.org/aging> (last visited May 25, 2015).

<sup>110</sup> *See* LORI STIEGEL & ELLEN KLEM, ABA COMM’N ON LAW & AGING, INFORMATION ABOUT LAWS RELATED TO ELDER ABUSE (2007), available at <http://bit.ly/106h05M>. “Each of the 50 states, the District of Columbia, Guam, Puerto Rico, and the Virgin Islands have authorized adult protective services statutes. These statutes vary widely based on who may be eligible for services and the types of abuse that may be actionable. At the same time, federal laws, such as the Older Americans Act, do little more than authorize funds for local awareness and coordination endeavors.” *See* 42 U.S.C. § 3002 (2006 & Supp. 2012). Unlike federal laws on child abuse and domestic violence, which fund services and shelters for victims, there is no comparable federal law on elder abuse.

<sup>111</sup> *See, e.g.*, HAW. REV. STAT. § 346-223, § 412:3-114 (2012).

<sup>112</sup> *Id.* Section I, modifying HAW. REV. STAT. § 346-221: While advanced age alone is not sufficient reason to intervene in a person’s life, the legislature finds that many elders have become subjects of abuse, neglect, and

which means a person eighteen years of age or older who, because of mental, developmental, or physical impairment, is unable to:

- Communicate or make responsible decisions to manage the person’s own care or resources;
- Carry out or arrange for essential activities of daily living; or
- Protect oneself from abuse.<sup>113</sup>

Under the law, “abuse” means any of the following, separately or in combination:

- Physical abuse,
  - Psychological abuse,
  - Sexual abuse,
  - Financial exploitation,
  - Caregiver neglect, or
  - Self-neglect.
- “Caregiver neglect” means the failure of a caregiver to exercise that degree of care for a vulnerable adult that a reasonable person with the responsibility of a caregiver would exercise within the scope of the caregiver’s assumed, legal, or contractual duties, including but not limited to the failure to:
    - Assist with personal hygiene,
    - Protect the vulnerable adult from abandonment,
    - Provide, in a timely manner, necessary food, shelter, or clothing,
    - Provide, in a timely manner, necessary health care, access to health care, prescribed medication, psychological care, physical care, or supervision;
    - Protect the vulnerable adult from dangerous, harmful, or detrimental drugs,
    - Protect the vulnerable adult from health and safety hazards, or
    - Protect the vulnerable adult from abuse by third parties.<sup>114</sup>
  - “Self-neglect” means: A vulnerable adult’s inability or failure, due to physical or mental impairment, or both, to perform tasks essential to caring for oneself, including but not limited to:
    - Obtaining essential food, clothing, shelter, and medical care,
    - Obtaining goods and services reasonably necessary to maintain minimum standards of physical health, mental health, emotional well-being, and general safety,
    - Management of one’s financial assets, and
    - The vulnerable adult appears to lack sufficient understanding or capacity to make or communicate responsible decisions and appears to be exposed to a situation or condition that poses an immediate risk of death or serious physical harm.<sup>115</sup>

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exploitation. Substantial public interest exists to ensure that this segment of the population receives protection.

<sup>113</sup> Haw. Rev. Stat. §346-224 (2009).

<sup>114</sup> *Id.*

<sup>115</sup> Haw. Rev. Stat. §346-222 (2009) (Definitions).

Intervention is initiated by a report to the Department of Human Services' ("DHS") Adult Intake.<sup>116</sup> If the abuse criteria are met, the report is sent to the Adult Protective Services Unit of DHS for investigation.<sup>117</sup> However, DHS must have the consent of the victim before an investigation or protective action can commence.<sup>118</sup> The law provides penalties for mandated reporters who fail to report<sup>119</sup> and immunities from liability for those who do report.<sup>120</sup>

Questions often arise whether attorneys should report abuse.<sup>121</sup> The Hawaii Adult Protective Service Act requires mandatory reporting for certain persons who, in the performance of their professional or official duties, know of or have reason to believe that a vulnerable adult has been abused and is threatened with imminent abuse.<sup>122</sup> The report may be made by a mandated reporter<sup>123</sup> or any other person who has reason to believe that a vulnerable adult has incurred abuse or is in danger of abuse if immediate action is not taken.<sup>124</sup> If the abuse criteria are met, the report is sent to the Adult Protective Services Unit of DHS for investigation,<sup>125</sup> but, DHS must have the consent of the victim before an investigation or protective action can commence.<sup>126</sup> A person mandated to make a report who knowingly fails to do so, or willfully prevents another from reporting the abuse may be subject to prosecution and may be guilty of a petty misdemeanor.<sup>127</sup> Further, immunity is granted to anyone making a report in good faith who might otherwise have incurred liability.<sup>128</sup>

The goal of protective services offered by the department is to remedy abuse, neglect, or exploitation of vulnerable adults.<sup>129</sup> Hawaii administrative rules provide the details of how adult protective services are provided throughout the state upon receiving a report.<sup>130</sup>

Adult Protective Services is required to investigate all reports of abuse or potential abuse and has the authority to prevent any future abuse.<sup>131</sup> In Hawaii, financial exploitation comprises the third highest number of adult abuse investigations. A vast majority of the victims in those investigations were older adults. In 2009, the Hawaii legislature passed a law that requires financial institutions to report suspected financial abuse of persons over age 62.<sup>132</sup>

### Ethical Issues

<sup>116</sup> HAW. REV. STAT. § 346-224 (2009).

<sup>117</sup> HAW. REV. STAT. § 346-227 (2009).

<sup>118</sup> HAW. REV. STAT. § 346-230 (2009).

<sup>119</sup> HAW. REV. STAT. § 346-224(e) (2009). See also note 126 *infra*.

<sup>120</sup> HAW. REV. STAT. § 346-250 (2009). See also note 127 *infra*.

<sup>121</sup> See note 142 *infra*.

<sup>122</sup> HAW. REV. STAT. § 346-224 (2015). The list does not include attorneys, but any person may report and the reports are confidential.

<sup>123</sup> *Id.* Mandated reporters include licensed or registered professionals of healing arts, physicians, nurses, pharmacists, employees or officers of any public or private agency or institution providing medical services, law enforcement, and employees or officers of any adult residential care home or similar institution.

<sup>124</sup> HAW. REV. STAT. § 346-224 (2009).

<sup>125</sup> HAW. REV. STAT. § 346-227 (2009).

<sup>126</sup> HAW. REV. STAT. § 346-230 (2009).

<sup>127</sup> HAW. REV. STAT. § 346-224(e) (2009).

<sup>128</sup> HAW. REV. STAT. § 346-250 (2009).

<sup>129</sup> Haw. Admin R. §17-1421-1.

<sup>130</sup> Haw. Admin. R. §17-1421-4 Geographic areas of service, provides that protective services for vulnerable adults shall be available throughout the State subject to the availability of resources.

<sup>131</sup> See *id.*

<sup>132</sup> HAW. REV. STAT. § 412:3-114 (2012).

Ethical issues abound for an elder law attorney as well as for a dementia-capable attorney. Ethical issues also affect the practices of other professionals in working with their patients/clients who may be an attorney's client. Understanding differences in ethical considerations can be important. As an example, health care professionals have ethical requirements to maintain confidences and to respect privacy, especially relating to their patients and the patients' caregivers.<sup>133</sup>

The ABA has developed Model Rules of Professional Conduct, which impose duties on attorneys in their practice of the law.<sup>134</sup> All states have rules of professional conduct and Hawaii's rules closely parallel those of the Model Rules.<sup>135</sup>

The most obvious question that an attorney and especially a dementia-capable attorney needs to ask is "Who is my Client?" The identification of the client is a fact-specific inquiry and is the first step in representation and, if the client is not court-appointed, it requires that the individual to be represented have sufficient capacity to retain the attorney. This decision may very well take the attorney in one direction or another.<sup>136</sup> Depending on the circumstances, the client may be the individual with dementia, a family member, a friend, a caregiver or other interested individual or entity.

Rule 1.1 of the Hawaii Rules of Professional Conduct imposes a duty to provide competent representation to a client.<sup>137</sup> This rule requires the attorney to have the legal knowledge, skill, thoroughness, and preparation reasonably required for the representation. Rule 1.2 requires an attorney to abide by a client's decisions concerning the objectives of the representation.<sup>138</sup> Rule 1.4 requires an attorney to communicate with the client.<sup>139</sup> For a client with dementia, section (b) of this rule is noteworthy, "A lawyer shall explain a matter to the extent reasonably necessary to permit the client to make informed decisions regarding the representation." Comment [6] to the rule provides, "Ordinarily, the information to be provided is that appropriate for a client who is a comprehending

<sup>133</sup> See, e.g., AM. PSYCH. ASS'N, COMMON ETHICAL ISSUES,

<http://www.apa.org/pi/about/publications/caregivers/practice-settings/ethical-issue/index.aspx?tab=1> ("Issues of privacy, informed consent, access to hospitalized or residential care patients, access to medical records or inclusion in conferences with healthcare staff, competency and decision making about care, especially end-of-life care may lead to complex, ethical conflicts or concerns when treating family caregivers.")

<sup>134</sup> See generally MODEL RULES OF PROF'L CONDUCT (1983).

<sup>135</sup> Hawaii Rules may be found at [http://www.courts.state.hi.us/docs/court\\_rules/rules/hrpcond.htm](http://www.courts.state.hi.us/docs/court_rules/rules/hrpcond.htm).

<sup>136</sup> Issues of autonomy and self-determination vs. protection and the best interest of an individual may arise, especially relating to contentious issues of impaired driving or emotional issues such as "pulling the plug" at the end of life. Such issues are not unique to the dementia-capable attorney. See, e.g., Josephine Ross, *Autonomy Versus a Client's Best Interests: The Defense Lawyer's Dilemma*, 35 AM. CRIM. L. REV. 1343, 1343 (1998) (A defense attorney articulates the difficulty with choosing between raising the defense of nonresponsibility against the client's wishes, when the attorney believes the client is suffering from a mental illness, and therefore is unable to follow sound advice.) See also Roberta K. Flowers, *Ethical Obligations When Representing a Person Alleged to Be Incapacitated*, NAELA News Jul/Aug/Sept 2015. [https://www.naela.org/Public/Library/Publications/Publications\\_Main/NAELA\\_News\\_Archive/NAELA\\_Jul\\_AugSept2015/Practical\\_Ethics.aspx](https://www.naela.org/Public/Library/Publications/Publications_Main/NAELA_News_Archive/NAELA_Jul_AugSept2015/Practical_Ethics.aspx). Last visited September 20 2015. ("Three ethical issues may develop in the context of this type of representation: 1) the requirement that an attorney represent the client's objectives under ABA Model Rule 1.2; 2) the provisions under ABA Model Rule 1.14; and 3) the attorney's obligations under ABA Model Rule 3.3 to not mislead the court.")

<sup>137</sup> HAW. RULES OF PROF'L CONDUCT R. 1.1 (amended 2013).

<sup>138</sup> HAW. RULES OF PROF'L CONDUCT R. 1.12 (amended 2013).

<sup>139</sup> HAW. RULES OF PROF'L CONDUCT R. 1.4 (amended 2013).

and responsible adult.”<sup>140</sup> However the next comment provides, “fully informing the client according to this standard may be impracticable, for example, where the client is a child or suffers from diminished capacity.”<sup>141</sup> When the client is an organization or group, it is often impossible or inappropriate to inform every one of its members about its legal affairs; ordinarily, the lawyer should address communications to the appropriate officials of the organization.<sup>142</sup> “Where many routine matters are involved, a system of limited or occasional reporting may be arranged with the client.”<sup>143</sup>

Rule 1.6 imposes a duty of confidentiality on lawyers, allowing them to disclose information related to representation of a client only in very limited circumstances, such as when the client gives informed consent or the disclosure is “impliedly authorized in order to carry out the representation.”<sup>144</sup> This rule allows lawyers to keep third parties out of their consultations with their clients, including family members of the client. Maintaining the confidentiality of lawyers’ communication with their clients can help safeguard against outside parties unduly influencing their clients’ legal decisions because, under this rule, lawyers cannot reveal what was discussed one-on-one with their clients or the particulars of the legal documents drafted for their clients.

Rule 1.7 provides that a lawyer shall not represent a client if the representation involves a concurrent conflict of interest.<sup>145</sup> Addressing issues relating to multiple representations, the rule provides that when representation of multiple clients in a single matter is contemplated, the consultation shall include explanation of the implications of the common representations, including both the advantages and the risks involved.<sup>146</sup> As to the duty of confidentiality, there are several considerations with respect to multiple or common representation.<sup>147</sup>

Rule 1.8 addresses conflicts (which may arise when dealing with families and caregivers).<sup>148</sup>

Additionally, Rule 1.14 provides that, when a client has diminished capacity, the lawyer should maintain a normal relationship with them as much as possible, with caveats:

When a client’s capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.

When the lawyer reasonably believes that the client has diminished capacity, is at risk of substantial physical, financial or other harm unless action is taken and cannot adequately act in the client’s own interest, the lawyer may take reasonably necessary protective action, including consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem, conservator or guardian.

Information relating to the representation of a client with diminished capacity is protected by Rule 1.6. When taking protective action pursuant to paragraph (b), the lawyer is impliedly authorized

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<sup>140</sup> HAW. RULES OF PROF’L CONDUCT R. 1.4, comment 6 (amended 2013).

<sup>141</sup> HAW. RULES OF PROF’L CONDUCT R. 1.14 (amended 2013).

<sup>142</sup> HAW. RULES OF PROF’L CONDUCT R. 1.13 (amended 2013).

<sup>143</sup> HAW. RULES OF PROF’L CONDUCT R. 1.4, comment 6 (amended 2013).

<sup>144</sup> HAW. RULES OF PROF’L CONDUCT R. 1.6 (amended 2013).

<sup>145</sup> HAW. RULES OF PROF’L CONDUCT R. 1.7 (amended 2013).

<sup>146</sup> HAW. RULES OF PROF’L CONDUCT R. 1.7(c) (amended 2013).

<sup>147</sup> HAW. RULES OF PROF’L CONDUCT R. 1.7, comment 30-31 (amended 2013).

<sup>148</sup> HAW. RULES OF PROF’L CONDUCT R. 1.8(f) (amended 2013) “A lawyer shall not accept compensation for representing a client from one other than the client unless: (1) the client consents after consultation; (2) there is no interference with the lawyer’s independence of professional judgment or with the client-lawyer relationship; and (3) information relating to representation of a client is protected as required by Rule 1.6.”

under Rule 1.6(a) to reveal information about the client, but only to the extent reasonably necessary to protect the client's interests.

This rule strengthens the lawyer's obligation to the client. As stated in Rule 1.14, "the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client."<sup>149</sup> Just because the client may have some kind of disability does not end the lawyer's obligation to the client. As mentioned in comment three to the rule, the lawyer must keep the client's interest as his or her main priority at all times, even when family members or other persons participate in discussions with the lawyer. This rule also gives the lawyer the option to take protective action if he or she believes that the client has diminished capacity and is at risk of substantial physical or financial harm. Some suggested actions listed in the commentary to this rule include the following: "consulting with family members . . . using voluntary surrogate decision-making tools such as durable powers of attorney or consulting with support groups. . . ."<sup>150</sup> However, it is important to remember the "guiding principle for the lawyer should be to take the least restrictive action."<sup>151</sup> Furthermore, the language of Rule 1.14 explicitly states that the "lawyer may take reasonably necessary protective action. . . ."<sup>152</sup> The problem is that there is no definition of "reasonably necessary," leaving it up to the lawyer to define.<sup>153</sup>

Comment six to Rule 1.14 mentions factors in determining the extent of the client's diminished capacity. These factors include the following: "the client's ability to articulate reasoning leading to a decision, variability of state of mind and ability to appreciate consequences of a decision; the substantive fairness of a decision; and the consistency of a decision with the known long-term commitments and values of the client."<sup>154</sup> Thus, the comments help to give some insight for lawyers to determine if, and when, an elderly or disabled client has diminished capacity.

Yet another issue facing the attorney whose client has physical or mental limitations affecting the client's ability to communicate, understand and evaluate information is the amount of time it may take to help that client. What may ordinarily be communicated in a short period of time may take much longer with a client who has physical or mental limitations. The client may also have periods where they are more alert or lucid and the attorney would need to schedule appointments around those times. These and other factors necessarily factor into costs and, for example, whether an attorney should bill hourly or simply charge a flat fee.

### Research Issues

Alzheimer's Disease has no known cure and has a devastating effect not only on patients but also on caregivers and society,<sup>155</sup> which leads to a conclusion that research in the field of dementia, and especially with such devastating diseases as Alzheimer's Disease, can be of benefit to society as well as to individual patients. For society, finding ways to prevent, treat and cure the

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<sup>149</sup> HAW. RULES OF PROF'L CONDUCT R. 1.14 (amended 2013).

<sup>150</sup> *Id.*

<sup>151</sup> Elizabeth Laffitte, Note, *Model Rule 1.14: The Well-Intended Rule Still Leaves Some Questions Unanswered*, 17 *Geo. J. Legal Ethics* 313, 328 (2004).

<sup>152</sup> HAW. RULES OF PROF'L CONDUCT R. 1.14 (amended 2013).

<sup>153</sup> Elizabeth Laffitte, Note, *Model Rule 1.14: The Well-Intended Rule Still Leaves Some Questions Unanswered*, 17 *Geo. J. Legal Ethics* 313, 328 (2004).

<sup>154</sup> MODEL RULES OF PROF'L CONDUCT R. 1.14 cmt. 6 (amended 2013).

<sup>155</sup> Note 28, *supra*.

disease would be welcome.<sup>156</sup> For the individual patient, having access to experimental medicines may be important.<sup>157</sup> Either way, in order to enroll in a research project, informed consent must be provided. The question often becomes, “Does the individual have the requisite capacity to volunteer to be a subject of human research studies?” Depending on whether the research is “therapeutic” or “non-therapeutic,” and depending on state law, the answer may be more complex than for capacity to make health care decisions. A significant number of health care providers are involved in research activities with their patients or individuals who are not their patients. Research into areas such as Alzheimer’s Disease is especially in the forefront of science.<sup>158</sup> For some investigators, research activities will involve treatment, and for others no treatment will be involved. Sometimes this distinction is referred to as therapeutic and non-therapeutic research. Nevertheless, federal regulations govern research on all human subjects whether the research involves treatment or not. Federal regulations mandate Institutional Review Boards for the Protection of Human Subjects (“IRBs”).<sup>159</sup> IRBs have been established at several institutions in Hawaii including the University of Hawaii.<sup>160</sup>

The primary concern of the research investigator is the safety of research participants, also referred to as research subjects. Consent must be voluntary and research subjects need to be able to carefully consider the risks involved versus the benefit to be attained. Some basic elements of informed consent include providing the following to each subject:

(1) A statement that the study involves research, an explanation of the purposes of the research and the expected duration of the subject's participation, a description of the procedures to be followed, and identification of any procedures which are experimental.

(2) A description of any reasonably foreseeable risks or discomforts to the subject.

(3) A description of any benefits to the subject or to others which may reasonably be expected from the research.

(4) A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject.

(5) A statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained and that notes the possibility that the Food and Drug Administration may inspect the records.

(6) For research involving more than minimal risk, an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained.

(7) An explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and whom to contact in the event of a research-related injury to the subject.

(8) A statement that participation is voluntary, that refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled, and that the subject may

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<sup>156</sup> See Honor Whiteman, *Alzheimer's disease: are we close to finding a cure?* MED. NEWS TODAY (last updated Aug. 20, 2014) <http://www.medicalnewstoday.com/articles/281331.php>.

<sup>157</sup> Sheng Chen, Current Experimental Therapy for Alzheimer’s Disease, 5 CURR. NEUROPHARMACOL. 127 (2007) available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2435347/>.

<sup>158</sup> ALZHEIMER’S ASS’N, RESEARCH CENTER, <http://www.alz.org/research/> (last visited 5/25/2015).

<sup>159</sup> See 45 C.F.R. §46.101 (2015).

<sup>160</sup> See OFFICE OF RES. COMPLIANCE, INST. REVIEW BD., UNIV. OF HAW. AT MANOA, <https://manoa.hawaii.edu/researchcompliance/institutional-review-board-irb-0>.

discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled.<sup>161</sup>

Accordingly, investigators must obtain informed consent from each research subject using all relevant information available and provide the subject the opportunity to ask questions of the investigator.<sup>162</sup> Consent is usually in writing. Adult research subjects who are mentally capacitated provide their own consent to participate in research activities. Difficult questions arise when the research subject becomes mentally incapacitated or when a research investigator would like to engage in research involving a mentally incapacitated person.

Federal regulations state: “No investigator may involve a human being as a subject in research covered by these regulations unless the investigator has obtained the legally effective informed consent of the subject or the subject’s legally authorized representative.”<sup>163</sup> The federal regulation defines “legally authorized representative” as “an individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject’s participation in the procedure(s) involved in the research.”<sup>164</sup>

If a current research subject is mentally capacitated, researchers may wish to consider obtaining consent for the continuation of future research or requesting that the subject consider designating an agent with power to consent to research in the event the subject should become mentally incapacitated. This would be particularly helpful for research activities involving older persons and person with conditions such as dementia. For persons who are not mentally capacitated and who have not provided consent or otherwise granted authority for such consent, researchers can

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<sup>161</sup> 21 C.F.R. § 50.25 (2015). See also OFFICE FOR HUMAN RES. PROTECTIONS, TIPS ON INFORMED CONSENT, <http://www.hhs.gov/ohrp/policy/ictips.html> (last visited May 25, 2015). OHRP provides a helpful explanation of informed consent:

Informed consent is a process, not just a form. Information must be presented to enable persons to voluntarily decide whether or not to participate as a research subject. It is a fundamental mechanism to ensure respect for persons through provision of thoughtful consent for a voluntary act. The procedures used in obtaining informed consent should be designed to educate the subject population in terms that they can understand. Therefore, informed consent language and its documentation (especially explanation of the study’s purpose, duration, experimental procedures, alternatives, risks, and benefits) must be written in “lay language,” (i.e., understandable to the people being asked to participate). The written presentation of information is used to document the basis for consent and for the subjects’ future reference. The consent document should be revised when deficiencies are noted or when additional information will improve the consent process.

The Office of Human Research Protections (“OHRP”) “provides leadership in the protection of the rights, welfare, and well-being of subjects involved in research conducted or supported by the U.S. Dept. of Health & Human Services.” OFFICE FOR HUMAN RES. PROTECTIONS, U.S. DEP’T OF HEALTH & HUMAN SERVS. <http://www.hhs.gov/ohrp/index.html> (last visited May 25, 2015).

<sup>162</sup> *Handbook for Lawyers*, *supra* note 54, at 133. See, e.g., Daniel Marson, University of Alabama at Birmingham. “Competency Assessment Checklist for Research Informed Consent,” 11 October 2002. This checklist is designed for briefly assessing and documenting research consent capacity. It is conceptually derived from the work of Appelbaum/Grisso and embeds in interview format the four core consent capacities linked to decisional capacity, namely, (1) understanding of the research protocol, including risks/benefits of participation, (2) making a choice to participate/not participate in research protocol, (3) showing an appreciation of the personal risks/benefits of participation/non-participation in the protocol, and (4) showing reasoning/providing rational reasons for participation/non-participation in the research protocol.

<sup>163</sup> 21 C.F.R. § 50.20 (2015).

<sup>164</sup> 45 C.F.R. § 46.102(c) (2015).

request court approval. This approach is cumbersome and uncertain since courts would require that court appointed guardians make decisions based on the “best interests” of the incapacitated person. Research activities may or may not be considered in the best interest of the person. For therapeutic research, the use of individual instructions for healthcare and agents designated in advance directives may be effective, especially if the issue of research is directly addressed.

In Hawaii, under the UHCDA, as will be discussed in greater detail later, the patient, or a guardian or an agent under a healthcare power of attorney or a designated or non-designated surrogate can provide informed consent for healthcare decisions. Also, as previously indicated, the definition of healthcare under the UHCDA is very broad. An expansive reading of the UHCDA could include research activities involving healthcare issues. However, research activities, whether therapeutic or non-therapeutic are not specifically addressed under the UHCDA. Research subjects who volunteer to participate in research activities involving healthcare issues usually will have a primary physician for their healthcare and researchers will often coordinate their activities with the primary physician.<sup>165</sup> The primary physician can be helpful in determining who is a legally authorized decision-maker for the patient. Researchers are cautioned to seek advice from their legal counsel and IRB when considering research on mentally incapacitated individuals.<sup>166</sup>

### **Selected Legal Topics for Dementia-Capable Attorneys**

As previously indicated, dementia-capable attorneys need to be able to address a plethora of legal issues. This discussion of legal topics will not attempt to qualify an attorney in any particular area of law. To the contrary, reliance on this section for substantive law matters would be foolhardy as explanations of most areas are shallow. One example in particular is health care financing, including Medicare and Medicaid. These two benefit areas are so complex and are so subject to change that a little knowledge can be dangerous. The main purpose of this section is to highlight areas of concern and further investigation, not to provide a practice manual.<sup>167</sup>

### **Guardianship, Conservatorship and Alternatives**

Understanding the role a guardianship, conservatorship, as well as their alternatives, can play may provide a valuable base for becoming a dementia-capable attorney. A guardianship of the person or a conservatorship of the estate<sup>168</sup> is a legal relationship often involving the loss of control, autonomy, and privacy for the individual for whom the appointment of a guardian or conservator is sought. It also can include significant time delays, and costs for the person or entity seeking to be a guardian for the potential ward or protected person.<sup>169</sup> There is an increasing recognition that persons

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<sup>165</sup> This leads to yet other legal issues such as privacy and confidentiality and the interrelation of federal laws (e.g., the federal HIPAA and state health privacy laws.).

<sup>166</sup> See e.g., HUMAN STUDIES, OFFICE OF RES. COMPLIANCE, UNIV. OF HAW. AT MANOA, <https://manoa.hawaii.edu/researchcompliance/human-studies> (last visited May 25, 2015).

<sup>167</sup> For Hawaii attorneys, the Hawaii State Bar Association (“HSBA”) provides a wide range of continuing legal education opportunities and training materials. The HSBA co-sponsored the first training in Hawaii on “Dementia Capable Attorneys” in February 2015. See <http://hsba.org/images/hsba/CLE/Flyers/Dementia%20Flyer.pdf>.

<sup>168</sup> These terms will sometimes collectively be called “guardianship.” Guardianship of the property is called “conservatorship” in many jurisdictions, including Hawaii.

<sup>169</sup> Negative aspects of guardianship can be more hypothetical than real. For example, the question of expenses may or may not be an issue in jurisdictions or in selected segments within jurisdictions that provide free legal

with disabilities, including persons with dementia, should be entitled to adequate levels of assistance and support to protect them from abuse and to help them exercise their rights to retain their own capacity to make decisions and to take action on their own behalf, including representing themselves in court, deciding where they should live, entering into contracts, voting, and making health care decisions. Utilizing alternatives to guardianship and supported decision-making frameworks may help address these concerns.

In general, courts may appoint a guardian only if it finds that a person is incapacitated and that the person's needs cannot be met by less restrictive means, including use of appropriate technological assistance. Further, in many jurisdictions, guardianship laws require that courts grant to a guardian only those powers necessitated by the ward or protected person's limitations and demonstrated needs and make appointive and other orders that will encourage the development of the ward or protected person's maximum self-reliance and independence.<sup>170</sup> On the other hand, a growing movement suggests that guardianship marginalizes the individual and imposes a form of segregation, violating the basic principles supporting autonomy and delivering services in the most integrated and least restrictive manner.

Alternatives to guardianship can be viewed both from the perspective of the protected person and from the perspective of the guardian or conservator. Guardianship can be a complicated and lengthy process. In the United States, for example, obtaining the required documents (such as birth certificates, marriage certificates, and doctor's assessment), going through the judicial process, giving notice to the interested parties, and attending the court proceedings normally takes several months. Filing fees and attorneys' fees and costs are normally incurred with each proceeding. Further, guardianship documents and proceedings and reports are often matters of public record and, accordingly, the financial affairs of the ward or protected person may become public knowledge.

With proper advance planning, guardianship proceedings may not be necessary if less restrictive alternatives can serve the purpose of providing necessary assistance to an incapacitated adult. Broadly, alternatives can be categorized as those that support the individual as the decision-maker, those in which decision-making responsibility is shared with the individual, or those in which the individual or an appointing authority delegates decision-making authority. As will be discussed, there are distinct advantages and disadvantages to the use of alternatives to guardianship. There are also distinct advantages and disadvantages within the variety of potentially available alternatives to guardianship. Finally, more than one alternative to guardianship may be required to perform tasks that a guardian may normally be empowered by a court to take on behalf of an incapacitated person.

Powers of attorney, representation agreements, advance directives for health care, trust arrangements, appointed fiduciaries or representative payeeships, and joint financial accounts to pay bills are a few of the frequently used alternatives. In the broadest sense, limited guardianship and "co-decision making" can be considered alternatives to guardianship. Each alternative comes with its own costs and trade-offs, advantages and disadvantages, benefits and risks, positives and

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services and the question of time may be of no significance to individuals who are permanently unconscious and who are being cared for but require guardians to assume legal responsibility for their continuing care.

<sup>170</sup> Guardianship proceedings in most states of the United States are governed by one version or another of Part V of the "Uniform Probate Code" commonly referred to as the UPC. The UPC is a uniform act drafted by the National Conference of Commissioners on Uniform State Laws ("NCCUSL") governing inheritance and the decedents' estates in the United States plus protection of persons under disability and their property. The primary purposes of the act were "to streamline the probate process and to standardize and modernize the various state laws governing wills, trusts, intestacy and guardianship." HAW. REV. STAT. §560:5-311 (1996). See UNIF. PROBATE CODE §§1-101 et seq., 8 U.L.A. 24 (1998).

negatives. In a practical sense, setting up effective alternatives to guardianship requires careful thought and a bit of guessing, since one can never really know if all the personal, health care, legal, and financial needs of an individual are actually covered until the individual becomes incapacitated. In this sense, obtaining a guardianship could be considered as an “alternative to alternatives to guardianship,” thus completing the circle.

### **Powers of Attorney and Representation Agreements**

Powers of attorney and representation agreements are two types of legal documents that allow individuals to plan for the management of their personal, health care and financial matters upon future incapability. In those jurisdictions recognizing representation agreement forms, an adult may name a representative to help make decisions or make decisions on behalf of the adult, with respect to personal care and health care, the routine management of financial affairs and obtaining legal services for the adult and instructing counsel. The laws underlying naming such representatives typically provide for procedures for certification of the representative and for recognition of the authority of the representative to act on behalf of the person.<sup>171</sup>

Powers of attorney are probably the most popular and utilized alternatives to guardianship and they are probably the most abused of the alternatives.<sup>172</sup> A power of attorney is a written instrument through which a person (called the “principal,” “grantor” or “donor”) designates another person to be his or her agent (or “donee” or “attorney-in-fact”) and grants the agent authority to perform certain acts on the principal’s behalf.

Powers of attorney can be drafted to take effect immediately or on a future date or upon a future contingency. Accordingly, for purposes of serving as an alternative to a guardianship, a “springing” or contingent power of attorney can be drafted to take effect upon some subsequent future event such as upon the principal’s disability or incapacity. A power of attorney can be effective for a specific period or can be effective indefinitely, until death, which normally terminates a power of attorney.<sup>173</sup>

In most jurisdictions, mental disability or incapacity of the principal terminates a power of attorney unless the instrument contains a provision that states that the power will not be affected by such disability or incapacity.<sup>174</sup> As will be discussed, in some states like Hawai‘i, the statutory default is that a power of attorney is durable unless specifically stated otherwise in the document.<sup>175</sup> In some other states, there are usually certain specific words that need to be included in the power of attorney for it to be considered “durable.”<sup>176</sup>

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<sup>171</sup> See, e.g., provisions relating to representation agreements in British Columbia, Canada at <http://www.ag.gov.bc.ca/incapacity-planning/> (last visited May 25, 2015).

<sup>172</sup> See Linda Whitton, *Durable Powers as an Alternative to Guardianship: Lessons We Have Learned*, 37 STETSON L. REV. 7 (2007).

<sup>173</sup> In some jurisdictions powers of attorney can continue to be effective after death for certain purposes, for example, for organ donation. This is true in jurisdictions of the United States that have enacted the latest version of the Uniform Anatomical Gifts Act (“UAGA”) drafted for potential use in all of the states by the National Conference of Commissioners on Uniform State Laws. See REVISED UNIF. ANATOMICAL GIFT ACT (2006) §§1 et seq., 8A U.L.A. 42 (Supp. 2011).

<sup>174</sup> See Whitton, *supra* note 155. Hawaii no longer follows this standard but has adopted the Uniform Power of Attorney Act. See Uniform Power of Attorney Act, HAW. REV. STAT. § 551E (2014).

<sup>175</sup> HAW. REV. STAT. § 551E (2014).

<sup>176</sup> Phrases such as “these powers will not be affected by my disability or incapacity” or “these powers will only be effective upon my incapacity or disability” would serve to create a durable power of attorney. The latter

Some states, including Hawaii, have enacted the Uniform Power of Attorney Act or UPOAA.<sup>177</sup> The UPOAA defines the levels of authority granted in a power of attorney to the principal's agent. It requires the agent to act in good faith and within the scope of authority granted in the power of attorney. Under most circumstances, it requires that the powers be accepted within a certain period of time. It provides sample documents to be used to create a statutory form power of attorney. It repeals Chapter 551D, Hawaii Revised Statutes, the Uniform Durable Power of Attorney Act. This new law applies to a power of attorney created before, on, or after the effective date of this new chapter in the Hawaii Revised Statutes.<sup>178</sup>

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phrase would create a springing durable power of attorney which can be useful for individuals who do not want to grant powers effective immediately but who do want someone to have power in the event of incapacity or disability. For example, a power of attorney document can provide that the agent will only be authorized to act for the principal when the principal has been determined by one or more doctors to be disabled or incapacitated. However, problems may arise if the agent and doctors disagree as to when the disability or incapacity occurs. Practically speaking, of course, problems can also arise when the principal is incapacitated and the powers are abused. See Jennifer L. Rhein, *No one in charge: Durable powers of attorney and the failure to protect incapacitated principals*, 17 ELDER L. J. 165 (2009).

<sup>177</sup> HAW. REV. STAT. § 551E (2014).

<sup>178</sup> *UPOAA General Differences from Repealed UDPOA Act under Hawaii Law:*

- Defaults to the POA being durable. “Durable,” with respect to a power of attorney, means not terminated by the principal’s incapacity.
- Defaults to a POA becoming effective immediately [unless expressly provided otherwise in the POA].
- Revokes a spouse-agent’s authority upon divorce [unless expressly provided otherwise in the POA].  
[http://www.americanbar.org/content/dam/aba/events/law\\_aging/2014\\_Maui\\_Planningforincapacityandwrapupday1part5.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/events/law_aging/2014_Maui_Planningforincapacityandwrapupday1part5.authcheckdam.pdf)

*Protections for the Principal:*

- Provides for written confirmation [often via a letter from the principal’s doctor] that the contingency that triggers the POA to be activated [often incapacity of the principal] has occurred.
- Provides that in the event the principal becomes incapacitated, the agent’s authority continues until revoked or amended by the court (rather than by a court-appointed fiduciary or conservator).
- Includes a list of “hot powers” that the agent may not perform without express authority in the POA because they present a great risk to the principal’s assets or estate. For example – gift giving or changing beneficiary designations.
- Provides default standards for the fiduciary duties of the agent but permits the principal to alter some parts of that default fiduciary standard.
- Includes safeguards against abuse by agent & includes remedies & sanctions for abuse by agent.
- Requires notice by an agent when agent is no longer willing or able to act.

*Protections for the Agent:*

- Provides a presumption that the POA is valid if properly acknowledged [for instance, by banks].
- States that an agent who acts with “care, competence and diligence” for the best interests of the principal shall not be liable solely because the agent also benefits or has an individual or conflicting interest in the principal’s property.

Powers of attorney come in two basic types: “general” and “special.” A general power of attorney is a very broad and sweeping grant of authority and is normally intended to grant virtually all of the powers to an agent that the principal possesses. This is the reason general powers of attorney are most often utilized as alternatives to guardianship—they theoretically can handle any personal, legal or financial situation that may come up. The principal should use such a broad delegation of power with caution since, unless prescribed by law or regulation, this instrument authorizes the agent to do any legal act that the principal might do. In contrast, a special power of attorney grants authority to an individual to act in specific matters. A special power of attorney is often used to allow an agent to handle specific situations when the principal is unavailable or unable to act. For example, the principal may be traveling outside the state or country, or may be unable to handle a specific situation because of other commitments or health reasons. Since it is limited in scope, the use of a special power of attorney reduces some of the risks involved in giving another person power but it is not always very helpful as an effective alternative to guardianship.

Powers of attorney are relatively simple to draft and to execute and do not require any court involvement.<sup>179</sup> While some guardianship proceedings take weeks and months to pursue, powers of attorney can be accomplished very quickly. Very often powers of attorney are “do-it-yourself” types of documents that are as easily found over the Internet as they have been easily found in stationery stores for years. Accordingly, they are usually inexpensive, even if drafted by an attorney. This easy access directly leads to some of the inherent danger, namely abuse of powers of attorney.

In addition to the inexpensive nature of powers of attorney, these documents can be tailored in accordance with the known intentions and desires of the principal who can empower an agent of choice and who can put into place safeguards, accountability standards, and limitation of powers as the principal may deem appropriate. Unlike a guardian, whom a court appoints and who is usually

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- Provides that, unless there is a breach of duty by the agent, the agent shall not be liable if the value of the principal’s assets decline.
  - Provides that the agent shall be entitled to reasonable compensation and reimbursement for expenses incurred on behalf of the principal [unless expressly provided otherwise in the POA].

*Protections for the Persons Accepting the POA:*

*Persons asked to accept a POA must, within seven business days, either accept the POA or request an agent’s certification under penalty of perjury of any factual matter concerning the principal, agent, or power of attorney, an English translation of the power of attorney if the power of attorney contains, in whole or in part, language other than English; and an opinion of counsel as to any matter of law concerning the power of attorney if the person making the request provides in a writing or other record the reason for the request.*

- *Upon receipt of the requested information, the person must accept the POA within five business days and may not request additional information. However: A person may refuse to honor a POA if they have actual knowledge that the agent’s authority has been terminated, or if they in good faith believe the POA is not valid, or if they are aware of a report made to APS about possible abuse of the principal. A person who refuses to accept an acknowledged power of attorney may be subject to a court order mandating acceptance of the power of attorney and liability for reasonable attorney’s fees and costs incurred in any action or proceeding that confirms the validity of the power of attorney or mandates acceptance of the power of attorney.*

<sup>179</sup> Hawaii’s law provides a statutory form which may be used or modified. See HAW. REV. STAT. § 551E-51 (2014).

given plenary powers, the agent is selected by the principal prior to incapacitation and, presumably, is someone that the principal knows and whom the principal feels can be trusted. Accordingly, it is possible to grant powers to an agent that the court may be reluctant to grant to a guardian. For example, a principal may grant powers to the agent to self-gift under various circumstances.<sup>180</sup> Agents are considered fiduciaries and statutes often prescribe limitations to help protect the principal.<sup>181</sup>

<sup>180</sup> See, e.g. HAW. REV. STAT. § 551E-47 (2014) (providing criteria for gifting powers under Hawaii law). The difference between self-gifting and self-dealing can be difficult to differentiate and can also include built in adverse tax, estate planning and self-support problems.

<sup>181</sup> See, e.g. HAW. REV. STAT. § 551E-10 (2014) (Agent's Duties), HAW. REV. STAT. § 551E-51 (2014) (Statutory Form; Important Information for Agent).

#### Agent's Duties

When you accept the authority granted under this power of attorney, a special legal relationship is created between you and the principal. This relationship imposes upon you legal duties that continue until you resign or the power of attorney is terminated or revoked. You must:

- (1) Do what you know the principal reasonably expects you to do with the principal's property or, if you do not know the principal's expectations, act in the principal's best interest;
- (2) Act in good faith;
- (3) Do nothing beyond the authority granted in this power of attorney; and
- (4) Disclose your identity as an agent whenever you act for the principal by writing or printing the name of the principal and signing your own name as "agent" in the following manner:

...

Unless the Special Instructions in this power of attorney state otherwise, you must also:

- (1) Act loyally for the principal's benefit;
- (2) Avoid conflicts that would impair your ability to act in the principal's best interest;
- (3) Act with care, competence, and diligence;
- (4) Keep a record of all receipts, disbursements, and transactions made on behalf of the principal;
- (5) Cooperate with any person that has authority to make health-care decisions for the principal to do what you know the principal reasonably expects or, if you do not know the principal's expectations, to act in the principal's best interest; and
- (6) Attempt to preserve the principal's estate plan if you know the plan and preserving the plan is consistent with the principal's best interest.

#### *Termination of Agent's Authority*

You must stop acting on behalf of the principal if you learn of any event that terminates this power of attorney or your authority under this power of attorney. Events that terminate a power of attorney or your authority to act under a power of attorney include:

- (1) Death of the principal;
- (2) The principal's revocation of the power of attorney or your authority;
- (3) The occurrence of a termination event stated in the power of attorney;
- (4) The purpose of the power of attorney is fully accomplished; or
- (5) If you are married to the principal, a legal action is filed with a court to end your marriage, or for your legal separation, unless the Special Instructions in this power of attorney state that such an action will not terminate your authority.

Even if the principal has doubts about the potential agent but still wishes to grant that person certain powers, the principal can take those concerns into account and have an attorney draft safeguards into the document. These safeguards can include periodic reports, much like those generally required by courts for guardians. While the reports would not be to a court, at least there could be some mechanism to assure that the powers are utilized in a fiduciary capacity. In the same vein, as long as the principal is still competent, the principal can revoke or modify the power of attorney at any time. Guardianships, on the other hand, need to be revoked or terminated by court order or by other formal processes.

There are also distinct dangers or disadvantages to powers of attorney. Powers of attorney can be dangerous in the wrong hands even with statutory limitations and guidance. Across the world, there are increasing reports of financial abuse, exploitation, and theft through the use of powers of attorney. There have been efforts to combat such issues but the problems seem to be increasing rather than decreasing, perhaps due to hard economic times.<sup>182</sup> The principal should be especially careful when giving a power of attorney to someone to handle real estate matters. Although it is difficult to ascertain, the principal should make every effort to be certain that the agent is trustworthy and, of course, the principal should make sure to read and understand the document when signing it. If there are any doubts, the principal should not sign the document until the trustworthiness of the agent is assured or, assuming a lawyer is involved, that the lawyer drafting the document has built in sufficient protections in the document.<sup>183</sup> Nevertheless, the potential for fraud exists in every power of attorney arrangement, through self-dealing, embezzlement, and unlawful gifting. When an agent acts with the apparent authority granted by the power of attorney, it may be impossible to undo what the agent has done, especially if the principal is no longer capacitated and is unable to provide testimony one way or another about the principal's intentions in granting the authority. State laws,

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*Liability of Agent*

The meaning of the authority granted to you is defined in the Uniform Power of Attorney Act in chapter 551E, Hawaii Revised Statutes. If you violate the Uniform Power of Attorney Act in chapter 551E, Hawaii Revised Statutes or act outside the authority granted, you may be liable for any damages caused by your violation.

<sup>182</sup> See J. Bueno, *Reforming Durable Power of Attorney Statutes to Combat Financial Exploitation of the Elderly*, 16 J. OF THE NAT'L ACAD. OF ELDER LAW ATT'YS 20 (2003). To partially safeguard against abuse, some people include a "self-executing revocation date," which specifies an expiration date. However, this provision would not make the document one that would be considered to be very effective as an alternative to guardianship. Of course, it is wise to keep track of to whom the power of attorney is given and where the document is located. In most jurisdictions, the principal has the right to revoke, terminate, or modify the power of attorney at any time. Although it can be revoked either orally or in writing, to be safe, the revocation should be in writing and given to the agent and to any person or organization where it may have been used.

<sup>183</sup> As previously mentioned, powers of attorney forms are readily available over the Internet as they have been in stationery stores over the years. In some jurisdictions, such as Hawaii, there are statutory forms which are available free of charge and are required forms. Examples of statutory forms are found in the Uniform Power of Attorney Act drafted by the National Conference of Commissioners of Uniform State Laws. See UNIFORM LAW COMMISSION, NAT'L CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS <http://www.uniformlaws.org/Act.aspx?title=Power+of+Attorney> (last visited May 25, 2015).

as in Hawaii may provide for judicial relief to construe a power of attorney or review the agent's conduct and grant appropriate relief.<sup>184</sup> Agents may also be held liable for violations of the law.<sup>185</sup>

In addition to the potential for abuse, there are also certain drawbacks to relying on a power of attorney as an alternative to guardianship. Unless a jurisdiction has enacted the Uniform Durable Power of Attorney Act (as in Hawaii), generally there is no requirement for an individual or organization to accept a power of attorney. Hawaii provides that powers of attorney must be accepted under specific criteria under the law.<sup>186</sup> Organizations may have their own forms or preferred formats.<sup>187</sup>

Much like guardianships and with just a few exceptions, death automatically terminates the power of attorney. In jurisdictions that have adopted provisions similar to those found under the Uniform Anatomical Gifts Act<sup>188</sup> an agent under a health care power of attorney may donate a decedent's body or body parts even after death. It should be noted that in most jurisdictions durable powers of attorney can include health care powers but only if such powers are specifically stated in

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<sup>184</sup> See HAW. REV. STAT. § 551E-12 (2014) (Judicial relief).

(a) The following persons may petition a court to construe a power of attorney or review the agent's conduct, and grant appropriate relief:

- (1) The principal or the agent;
- (2) A guardian, conservator, or other fiduciary acting for the principal;
- (3) A person authorized to make health care decisions for the principal;
- (4) The principal's spouse, parent, or descendant;
- (5) An individual who would qualify as a presumptive heir of the principal;
- (6) A person named as a beneficiary to receive any property, benefit, or contractual right on the principal's death or as a beneficiary of a trust created by or for the principal that has a financial interest in the principal's estate;
- (7) A governmental agency having regulatory authority to protect the welfare of the principal;
- (8) The principal's caregiver or another person that demonstrates sufficient interest in the principal's welfare; and
- (9) A person asked to accept the power of attorney.

(b) Upon motion by the principal, the court shall dismiss a petition filed under this section, unless the court finds that the principal lacks capacity to revoke the agent's authority or the power of attorney.

<sup>185</sup> See HAW. REV. STAT. § 551E-13 (2014) (Agent's liability). An agent that violates this chapter shall be liable to the principal or the principal's successors in interest for the amount required to:

- (1) Restore the value of the principal's property to what it would have been had the violation not occurred; and
- (2) Reimburse the principal or the principal's successors in interest for the attorney's fees and costs paid on the agent's behalf.

<sup>186</sup> See HAW. REV. STAT. § 551E-16 (2014) ("A person that refuses to accept an acknowledged power of attorney in violation of this section shall be subject to: (1) A court order mandating acceptance of the power of attorney; and (2) Liability for reasonable attorney's fees and costs incurred in any action or proceeding that confirms the validity of the power of attorney or mandates acceptance of the power of attorney.")

<sup>187</sup> In the United States, the Internal Revenue Service has its own Power of Attorney Form 2848 that allows a person to authorize an agent to represent him or her before the IRS, receive and read confidential tax information and correspondence, sign returns and perform other actions related to tax returns. The Internal Revenue Service, Form 2848 Power of Attorney and Declaration of Representative (2014), <http://www.irs.gov/pub/irs-pdf/f2848.pdf> (last visited May 25, 2015).

<sup>188</sup> See REVISED UNIF. ANATOMICAL GIFT ACT, *supra* note 156.

the document, even if the document states that it is a general power of attorney and grants “all authority” to the agent. Information about “Durable Powers of Attorney for Health Care” will be discussed in detail later in this article.

### Trusts

Trusts are used in some jurisdictions to manage assets and, sometimes in the broadest sense of the term “trusteeship,” the authority to manage other aspects of a person by another person or an entity.<sup>189</sup> In this section, the term “trust” will be used in a more narrow sense, specifically as a legal mechanism to help manage assets of one person by another as an alternative to guardianship.<sup>190</sup> For simplicity, a trust will be defined as an arrangement a person (sometimes called the “settlor” or “trustor”) makes to give control of his or her property to a trustee (who could also be the settlor), who holds it for the benefit of the settlor and/or other beneficiaries. As with powers of attorney, there are a variety of types of trusts.<sup>191</sup>

An individual who is planning for incapacity can use a trust as an effective alternative to guardianship if it is recognized in the particular jurisdiction. If a person should become incompetent or incapable of handling his or her own affairs, the trust can be drafted to go into effect when needed and to utilize assets placed in the trust for the benefit of the person, thus avoiding the need to appoint a conservator. The trustee (or successor trustee) can be given instructions on how to utilize the property for the benefit of the beneficiary in accordance with the desires of the settlor. If the settlor and the beneficiary are the same person, that person’s autonomy and self-determination can be preserved even during periods of incapacity through the instructions incorporated into the trust.

As with powers of attorney, trusts are generally less expensive than guardianships, although trusts are generally more expensive than powers of attorney. Also like powers of attorney, trusts can be set up to avoid issues relating to the privacy of the individual setting up the trust, the persons or entities managing the trust and the person benefitting from the trust, i.e. for purposes of this article, the incapacitated person. In jurisdictions recognizing trusts, they are generally more accepted than powers of attorney but do not have the full effect of a court order obtained through a guardianship.

One of the most important considerations in setting up a living trust is to properly transfer into the trust the property that is to be managed. This can include a home and rental properties,

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<sup>189</sup> Many jurisdictions do not have a developed law of trusts, or the principles differ significantly among jurisdictions. The Hague Convention of 1 July 1985 on the Law Applicable to Trusts and on their Recognition is an attempt to foster understanding and effective use of trusts in the International setting. See [http://www.hcch.net/index\\_en.php?act=conventions.text&cid=59](http://www.hcch.net/index_en.php?act=conventions.text&cid=59). (Last visited May 25, 2015). Trusts are more likely to be utilized in Common Law countries but certain Civil Law countries such as France (since 2008), are beginning to recognize their use. See, e.g., Code civil [C.civ.] Titre XIV “De la fiducie” (Fr.), available at [http://www.legifrance.gouv.fr/affichCode.do;jsessionid=FBC68F48F6A9BEB85B0C96661DCE886.tpdjo13v\\_3?idSectionTA=LEGISCTA000006118476&cidTexte=LEGITEXT000006070721&dateTexte=20101009](http://www.legifrance.gouv.fr/affichCode.do;jsessionid=FBC68F48F6A9BEB85B0C96661DCE886.tpdjo13v_3?idSectionTA=LEGISCTA000006118476&cidTexte=LEGITEXT000006070721&dateTexte=20101009) (last visited May 25, 2015).

<sup>190</sup> In this sense the terms “conservatorship” or “guardian of the property” are most commonly used.

<sup>191</sup> Testamentary trusts are established in wills and are thus generally not very useful as alternatives to guardianship since the trust only becomes effective upon death. Usually a testamentary trust would only go into effect after an estate has been probated. Of course if a trust is established through the will of one party for the benefit of an individual who is or may become incapacitated, such a trust can be considered an alternative to guardianship since a trustee can manage the assets included in the trust for the benefit of the incapacitated person. Trusts established by a settlor while alive are called “living trusts” and can be established by an individual for the specific purpose of management of assets in the event of incapacity. Living trusts can be either revocable or irrevocable.

vehicles, bank and savings accounts, stocks and bonds, and virtually anything that is tangible and can be legally owned. Transferring title of the property to the trust is not automatic and often involves the services of an attorney. Once property is transferred into a trust, the trustee can use and manage the property in accordance with instructions in the trust. Unlike guardianships, in a trust, there is no court order that authorizes the transfer of authority over the property of the incapacitated person. Trusts that are not funded, that is to say, that do not include property to be managed for the benefit of the incapacitated person, are ineffective as alternatives to conservatorship.

Although a trustee may be seen as similar to a guardian in that both are fiduciarily responsible for the property entrusted to them, there are marked differences. A guardian is appointed by court and must follow the rules of the probate code and of the court, such as making yearly reports. In contrast, the individual settlor selects the trustee as well as the successor trustee and decides under what conditions the successor trustee will serve, what the terms of the trust are, whom the beneficiaries are and what if any reports are made. As previously mentioned, trusts are generally more readily accepted than powers of attorney. In contrast to powers of attorney, courts are more readily petitioned to intervene in cases where fiduciary responsibilities have been violated and often jurisdictions have well-established mechanisms for oversight, intervention and resolution of conflicts.<sup>192</sup> Although it is not uncommon for a court to intervene in cases of fraud or exploitation perpetrated by an agent under a power of attorney, such intervention is more often prescribed under a jurisdiction's penal code or adult protective services statutes.<sup>193</sup>

As with powers of attorney there are increasing reports of financial exploitation involving trusts but, unfortunately, the same can be said of guardianships.<sup>194</sup> In the past, trusts were primarily used as estate planning tools but are now seen as both an effective tool for estate planning as well as for planning for incapacity and avoiding guardianship.

### **Money Management, Informal Financial Arrangements and Appointed Fiduciaries**

One of the most common reasons that an older adult becomes the subject of guardianship and conservatorship proceedings is that the individual has difficulty handling his or her financial affairs and needs help with money management. Money management, a catch-all term for a wide range of services provided by individuals and organizations to help people manage their financial affairs, includes check writing, bill paying, depositing money, reconciling checkbooks, filing taxes and even financial counseling. Professional money management services are offered by financial institutions, professional and otherwise skilled money managers such as accountants, including certified public accountants, for profit and nonprofit organizations among others. Such individuals and organizations can be insured and bonded, thereby adding a level of protection for clients. Fees are normally charged although lower income individuals may be able to obtain free or reduced fee services. To plan for periods of future incapacitation, often such individuals or organizations will

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<sup>192</sup> See HAW. REV. STAT. § 554 et seq. (2014) (Trusts and Trustees, Accounts), HAW. REV. STAT. §560 et seq. (2012) (Uniform Probate Code), and HAW. REV. STAT. §556 et seq. (2012) (Uniform Fiduciaries Act).

<sup>193</sup> See HAW. REV. STAT. §708 et seq. (2012) (Offenses Against the Person) and HAW. REV. STAT §§ 346-221 to -253 (2012) (Adult Protective Services). “Financial exploitation” means the wrongful taking, withholding, appropriation, or use of a vulnerable adult’s money, real property, or personal property, including but not limited to (1) The breach of a fiduciary duty, such as the misuse of a power of attorney or the misuse of guardianship privileges, resulting in the unauthorized appropriation, sale, or transfer of property. . .” HAW. REV. STAT. §346-22 (2012).

<sup>194</sup> See The U.S. Gov’t Accountability Office Report, Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors (2010). <http://www.gao.gov/assets/320/310745.html> (last visited May 25, 2015).

request powers of attorney or suggest setting up a trust or otherwise establish a financial management arrangement by means of a contract.

An increasingly popular tool for very informal money management is the use of bank cards in automatic teller machines (“ATMs”) through the use of personal identification numbers (“PIN”) to obtain cash on behalf of a disabled person to buy groceries, to pay rent and to make other purchases and payments. This type of informal money management can last well beyond the capacity of the disabled person once the individual secures the PIN number. This mechanism can also be fraught with dangers of potential financial exploitation and theft.

Another simple alternative to the guardianship/conservatorship mechanism for financial purposes is the establishment of joint checking or savings or other financial accounts through which one or more persons are added to such accounts as owners or as persons who are authorized access to the account, usually by means of a contract and signature cards executed by the parties with the financial institution. Having a joint account with another person can be useful for someone who needs help in writing checks, making deposits or withdrawing cash because it gives the assisting person access to the funds. While it may be simple and convenient, this alternative can also be very risky because the person whose name is added to the account is generally considered a co-owner of the account and can withdraw all of the money at any time.

Although many people still pay bills and manage their investments through checks and other paper transactions, computers and the Internet have dramatically changed the way people take care of their finances. Electronic banking makes it possible to manage and access funds through electronic funds transfer, direct deposit, pay-by-phone systems, personal computer banking and debit card purchases, and to perform many other functions.

As with other alternatives to guardianship in the area of money management, many schemes and scams can be perpetrated, especially since Internet and telephone transactions do not occur face-to-face. Individuals should be warned about entrusting their ATM bank card to others, especially to people or companies they do not know.

When a person has memory loss, is incapacitated, or does not understand the process of paying bills or money management, an appointed fiduciary (sometimes called a “representative payee”) can be appointed to handle his or her government benefits. For example in the United States, upon appointment, the representative payee receives checks (or direct deposit of funds) from the Social Security Administration (“SSA”) and, similarly, the appointed fiduciary acts for a beneficiary of the Department of Veterans Affairs and must use the money for the needs of the beneficiary. Each agency has its own procedures for selecting, designating or appointing as well as monitoring a fiduciary who may or may not be a spouse or other family member and who may or may not be entitled to payment for services.

### **Co-Guardianship and Limited Guardianship**

If an adult’s ability to make decisions is diminished, but the adult is still able to make decisions with adequate support, a court may order a co-guardian (in some jurisdictions called a “co-decision-maker”) appointed to serve with the protected individual.<sup>195</sup> This may or may not be considered as an alternative to guardianship. The process still involves a court order, but it helps maintain the protected person’s autonomy by allowing her to continue to make decisions with the

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<sup>195</sup> The Province of Alberta, Canada serves as an example where co-decision-makers are encouraged and supported. See Government of Alberta, Co-Decision Making, <http://humanservices.alberta.ca/guardianship-trusteeship/co-decision-making-how-it-works.html> (last visited May 25, 2015).

assistance of another. Such orders require the consent of the protected person and the proposed co-guardian. Co-guardianship is usually considered appropriate for spouses, family members, and close friends. Likewise, a limited guardianship involves court intervention and an order but limits the powers of a guardian to those needed to address the particular disabilities of the person under protection while preserving the residual decision-making authority of the person.<sup>196</sup>

### **Supported Decision-Making**

Supported decision-making mechanisms may be informal or formal.<sup>197</sup> In some jurisdictions, if an adult has the capacity to make decisions but the individual desires some formal assistance, the individual may sign a document that authorizes another individual to be the individual's "supporter." This supporter may be given permission to access the individual's private information, including personally identifiable health care information normally protected under privacy laws. The supporter could be granted permission to assist the individual in making and communicating complex decisions about the individual's health care, personal, legal and financial matters. Such an alternative is appropriate for those individuals with mild cognitive impairments, including impairments due to mental disorders as well as those who have difficulty communicating, including those individuals whose first language is not that of the particular jurisdiction.

There is increasing momentum in the world community for supported decision-making. The United Nations has been at the forefront of this movement. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (the Convention) obliges signatory countries to replace guardianship systems with more rigorous systems of alternatives, including systems and methods of supported decision-making for individuals with disabilities.<sup>198</sup> Article 12 also recognizes

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<sup>196</sup> The Uniform Guardianship and Protective Proceedings Act ("UGPPA") supports such limitations by requiring judges to inquire into the abilities as well as the disabilities of the allegedly incapacitated person. UNIF. GUARDIAN AND PROTECTIVE PROCEEDINGS ACT OF 1997 §311, 8A U.L.A. 362 (2003) ("The court, whenever feasible, shall grant to a guardian only those powers necessitated by the ward's limitations and demonstrated needs and make appointive and other orders that will encourage the development of the ward's maximum self-reliance and independence.")

<sup>197</sup> In the broadest sense, provided services and assistance may range from companion, telephone assurance, transportation, medication management, home health, nutrition, housekeeping, respite, and case management, services to the assignment of dedicated supporters. The supported individual may have full or limited capacity.

<sup>198</sup> For implementation of this convention, *See* United Nations Enable, United Nations Secretariat, Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities ch. 6 (2007) *available at* <http://www.un.org/disabilities/default.asp?id=242>. With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual. This distinguishes supported decision-making from substituted decision-making, such as advance directives and legal mentors/friends, where the guardian or tutor has court-authorized power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in the individual's best interest or according to his/her wishes. Paragraph 4 of article 12 calls for safeguards to be put in place to protect against abuse of these support mechanisms.

Supported decision-making can take many forms. Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity."

that persons with disabilities have legal capacity on an equal basis with others but may require assistance to exercise this capacity. Accordingly signatory states are required to support individuals with and to provide safeguards against abuse of that support.<sup>199</sup>

The supported decision-making framework under Article 12 is distinguished from more entrenched substituted decision-making mechanisms, such as guardianship or traditional alternatives to guardianship such as powers of attorney, health advance directives, and health care surrogates where the person acting on behalf of the disabled person is granted the power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in conformance with the wishes or are even in the best interests of the disabled person.

There can be practical issues in supported decision-making frameworks, especially if an individual cannot identify or agree upon a trusted person or group of people to provide requested assistance. In addition, supported decision-making generally requires more resources to assure that personal autonomy and self-determination are respected. Accordingly, unless jurisdictions mandate a supported decision-making framework for disabled persons, chances for successfully implementing such programs may be limited.

### **Alternatives to Guardianship for Health Care Decision-Making**

The process for making medical treatment decisions revolves around the evolving concepts of informed consent and a person's right to accept or refuse unwanted medical treatment.<sup>200</sup> In some countries, an individual with decision-making capacity has the right to consent to or refuse any suggested medical treatment, even if refusal may result in death.<sup>201</sup> When an individual is no longer mentally capacitated, most jurisdictions require that a legally authorized representative make such decisions for the individual, except in an emergency. A guardian, of course, is a legally authorized representative for an individual but there are several alternatives to guardianship in the area of health care decision-making.

The use of advance directives as alternatives to guardianship has been an integral part of health care planning for years even though their effectiveness may continue to be questioned and compliance to patients' desires may still be somewhat inconsistent.<sup>202</sup> In the United States, as with other issues confronting the nation as a whole, the National Conference of Commissioners on

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<sup>199</sup> *Id.*

<sup>200</sup> Issues relating to informed consent, who is empowered to make medical treatment decisions and whether the patient's rights or preferences trump those of the health care provider or the patient's family, guardian, surrogate or community continue to vary around the world. The relatively new "Western" approaches to autonomy and self-determination are not universally accepted. See, for example, Robert Levine, *Informed Consent: Some Challenges to the Universal Validity of the Western Model*, *The Journal of Law, Medicine & Ethics*, Vol. 19, 207-213 (1991). These issues may arise even more intensely when regarding decision-making at the end of life. See, e.g., KATHRYN BRAUN, JAMES PIETSCH AND PATRICIA BLANCHETTE (eds.), *CULTURAL ISSUES IN END OF LIFE DECISION-MAKING* (1999).

<sup>201</sup> See, e.g., U.S. CONST. amend XIV; *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

<sup>202</sup> For example, in 2008, the U.S. Secretary of Health and Human Services provided a comprehensive report to Congress entitled "Advance Directives and Advance Care Planning." The report focused on (1) the best ways to promote the use of advance directives and advance care planning among competent adults as a way to specify their wishes about end-of-life care; and (2) addressing the needs of persons with disabilities with respect to advance directives. See U.S. DEP'T OF HEALTH & HUMAN SERVS., *ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS* (2008), <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf> (last visited May 25, 2015).

Uniform State Laws (“NCCUSL”) has addressed the area of health care decision-making, including decision-making for incapacitated individuals, by drafting the Uniform Health Care Decisions Act (“UHCDA”).<sup>203</sup> While most jurisdictions have not adopted the UHCDA, Hawaii has adopted a modified version.<sup>204</sup>

### **Individual Instructions and Health Care Powers of Attorney**

Under Hawaii law, an adult or emancipated minor may make advance health care directives by giving an “individual instruction”<sup>205</sup> orally or in writing and/or by executing a power of attorney for health care, which may authorize the agent to make any health care decision the principal could have made while having capacity. An individual may revoke the designation of an agent only by a signed writing or by personally informing the supervising health care provider,<sup>206</sup> but an individual may revoke all or part of an advance health care directive, other than the designation of an agent, at any time and in any manner that communicates an intent to revoke.<sup>207</sup> The law even provides an optional sample form (and explanation), which may be duplicated or modified to suit the needs of the person. Alternately, one may use a completely different form that contains the substance of the sample form found in the statute.<sup>208</sup>

As with the UHCDA, Hawaii law places the durable power of attorney for health care, and a surrogate consent law together in one statute. As mentioned in a previous section, powers of attorney for health care may be included in a general power of attorney. It can also be included in an advance health care directive or it can be a stand-alone document. A health care power of attorney, no matter where it is included, needs to comply with the health care decision-making law of the jurisdiction. This leads to one of the potential drawbacks of this document, namely “portability”—will the document be recognized in other jurisdictions? The UHCDA seeks to make such documents portable from one jurisdiction to another but this is not guaranteed and legal practitioners often create multiple documents for individuals who live for extended periods in different jurisdictions, most of which have not enacted the UHCDA.

An “individual instruction,”<sup>209</sup> applies to a wide range of health care decisions, not just end-of-life decisions. An individual instruction permits an individual to provide information to health care providers about health care decisions in the future, including desires with respect to artificially-provided nutrition and hydration (tube feeding) other life-sustaining treatments, pain management, mental health treatment and virtually any other health care decision that an individual could make if incapacitated. The residual decision-making portion of the Act is usually included in hierarchical or

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<sup>203</sup> See, e.g., HAW. REV. STAT. § 327E (1999). Only a minority of states in the United States have enacted this act but all states have laws, which practically address the provisions of the act.

<sup>204</sup> HAW. REV. STAT. § 327E-3 (1999).

<sup>205</sup> HAW. REV. STAT. § 327E-2 (1999) (defining an “Individual Instruction” as an individual’s direction concerning a health care decision for the individual).

<sup>206</sup> HAW. REV. STAT. § 327E-34(a) (1999).

<sup>207</sup> HAW. REV. STAT. § 327E-4(b) (1999).

<sup>208</sup> HAW. REV. STAT. § 327E-16 (1999).

<sup>209</sup> The term “living will,” was sometimes used in the past to refer to what is now called an individual instruction in an advance health care directive. While the use of the former term has been largely abandoned, it may still appear in some jurisdictions and may still be used by some organizations that have not changed to the more accurate and precise terminology. An example is the US Department of Veterans Affairs VA Form 10-0137, dated March 2011, “VA Advance Directive Durable Power of Attorney For Health Care and Living Will.” See <http://www.va.gov/vaforms/medical/pdf/vha-10-0137-fill.pdf> (May 25, 2015).

“family consent” provisions that have been adopted in a majority of the states of the United States. This applies only if there is no applicable individual instruction, guardian, or appointed health care agent.

Although advance directives are generally used in the context of making end-of-life decisions, the laws of the State of Hawaii cover a broad range of advance directives and make it easy for individuals to have their instructions followed. Accordingly, directions such as declining any cardiopulmonary resuscitation in the future or donating organs may be considered in a broad sense to be advance directives. Another example is a law which specifically addresses making decisions in advance with respect to mental health conditions. Most commonly, advance directives are thought of as those written documents which provide health care providers with information about a patient’s desires concerning medical treatment and which contain a designation of an agent to make health care decisions for the patient. Although written advance directives concerning life sustaining medical treatment are encouraged and preferred under Hawaii law, they are not required. An adult or emancipated minor may give an individual instruction regarding health care. The instruction, oral or written, may be limited to take effect only if a specified condition arises.

In Hawaii, advance health care directive formats generally follow the optional form found in Hawaii’s UHCDA. An advance health care directive is never required but it can be very helpful. Every state has different laws and formats and some health care facilities may be reluctant to recognize out-of-state documents. There continues to be a strong movement toward creating uniformity among the states and especially in the “portability” of documents. It is particularly important to take preventive measures and look into the laws in another state ahead of time if you are moving to another state or if you are planning to spend an extended period in that state. Some of this homework can be accomplished by looking the information up on the Internet, asking a relative or friend living in that area to find out from a health care provider, or asking an elder law attorney about advance directive guidelines and forms in that state.

Under Hawaii law, you can choose to have the powers in the health care power of attorney take effect when you become incapable of making your own decisions or you can have it take effect immediately even when you are still capable.<sup>210</sup> You may also name an alternate agent to act for you if your first choice is not willing, able, or reasonably available to make decisions for you. This is a very important consideration since you cannot always be sure your primary agent will be available to make decisions when you need him or her.

Unless related to you, your agent may not be an owner, operator, or employee of a health care institution where you are receiving care.<sup>211</sup> Unless the form you sign limits the authority of your agent, your agent may make all health care decisions for you. Practically speaking, a physician normally will not want to act or perhaps will not be able to act as your agent, unless you are related to the physician or if the physician is a close friend and is not your treating physician.

Powers of attorney for health care must be properly witnessed or notarized. For the power of attorney to be valid for making health care decisions, you must sign it before two “qualified” adult witnesses who are personally known to you and who are present when you sign and who must also sign the document, or you may sign the document before a notary public in the state that acknowledges your signature.

A witness for a power of attorney for health care cannot be a health care provider, an employee of a health care provider or facility, or the agent you have designated in your power of

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<sup>210</sup> HAW. REV. STAT. § 327E-3 (e) (1999).

<sup>211</sup> HAW. REV. STAT. § 327E-3(b) (1999).

attorney. At least one of the individuals used as a witness for a power of attorney for health care must be someone who is neither related to the principal by blood, marriage, or adoption, nor entitled to any portion of the estate of the principal upon the principal's death under any will or codicil the principal may have made prior to the execution of the power of attorney for health care or by operation of law then existing.<sup>212</sup>

### **Revocation/Effectiveness of Advance Health Care Directive**

The UHCDA makes it clear that you may revoke an advance directive, including a health care power of attorney. However, you may revoke the designation of an agent only by a signed writing or by personally informing the supervising health care provider. You may revoke all or part of an advance health care directive, other than the designation of an agent, at any time and in any manner that communicates intent to revoke. A decree of annulment, divorce, dissolution of marriage, or legal separation revokes a previous designation of a spouse as agent unless otherwise specified in the decree or in a power of attorney for health care.<sup>213</sup> Except for the donation of a decedent's body or body parts under Hawaii's Uniform Anatomical Gifts Act,<sup>214</sup> a health care power of attorney ceases to be effective upon the death of the principal.

### **Cultural Issues in End of Life Decision Making**

Hawaii's ethnic diversity makes for a very different society than is seen in the rest of the country. While Hawaii is in many ways a much more culturally, ethnically and racially blended society than the rest of the United States it is a society with its own set of cultural and social dilemmas.

A good example is the advance directive that ensures independence, autonomy and choice at the end of life. It may be considered inappropriate in certain South Pacific cultures for an individual to make these decisions by himself or herself. In some of these cultures, the chief of the group, not the individual, traditionally may be the person who makes all life and death decisions.

In some cultures a family consensus takes priority over an individual's decision regarding end of life medical treatment. In some Asian cultures, it is not uncommon for the eldest son to make these decisions for his parents. There is no right or wrong answer. We need to respect and accept these cultural differences and not force our beliefs on others.<sup>215</sup> To provide access to justice for our multi-ethnic clients, the University of Hawaii Elder Law Program ("UHELP") has had the advance directive translated into various languages, including Chinese, Japanese, Korean, Ilocano, Tagalog, Vietnamese, and Samoan.

Although the advance directive for health care, popularly called a "living will," may seem to be absent of controversy today, prior to its adoption in Hawaii and in other states, it was highly controversial and elicited public protests from conservative and religious groups.<sup>216</sup> To gain acceptance, a statewide campaign in Hawaii was launched to reach out to diverse ethnic and cultural groups. A coalition of religious, medical and community leaders advocated for its passage and averted strong public opposition. Today although it is a widely accepted legal document that

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<sup>212</sup> HAW. REV. STAT. § 327E-3 (d) (1999).

<sup>213</sup> HAW. REV. STAT. § 327E-4 (1999).

<sup>214</sup> HAW. REV. STAT. § 327 (1999).

<sup>215</sup> See, e.g., BRAUN, *supra* note 183.

<sup>216</sup> Lenora H. Lee, A Good Death: the Politics of Physician Assisted Suicide in Hawaii (Aug. 2009) (unpublished Ph.D. dissertation, University of Hawaii) (on file with author).

hospitals and other health care facilities distribute matter-of-factly to their patients as part of their standard procedures, we still need to be aware of our cultural and religious differences.

### Surrogate Decision-Making

Who can make health care decisions for an individual no longer capable of making decisions, has no designated health care agent and has no guardian? Historically, health care providers have turned to family members to provide informed consent in these situations. Hawaii has established a unique framework for appointing or selecting surrogates. Under the laws of many jurisdictions (and included within the provisions of the UHCDA adopted by several states), a surrogate may make a health care decision for a patient if the patient lacks capacity and no agent or guardian has been appointed or neither the agent nor guardian is available.<sup>217</sup> A patient may designate or disqualify any individual to act as a surrogate by personally informing the supervising health care provider. In the absence of such a designation, or if the designee is not reasonably available, a surrogate may be appointed to make a health care decision for the patient. Under UHCDA approved by the NCCUSL (but not Hawaii's version), in the absence of a designation, or if the designee is not reasonably available, any member of an enumerated list of classes of the patient's family who is reasonably available, in a descending order of priority, may act as surrogate.<sup>218</sup>

A variety of other approaches exist regarding who can make decisions for an incapacitated person if there is no guardian, agent, or designated surrogate. For example Hawaii has established a unique framework for appointing or selecting surrogates: its law provides for decision making by surrogates selected by consensus from a group of "interested persons."<sup>219</sup> In some jurisdictions, when an adult does not have the capacity to make a decision and does not have a guardian or advance directive, a health care provider (a physician, nurse practitioner, or dentist for dental care only), may choose a relative to act as a specific decision-maker and make the necessary decision on behalf of the adult.<sup>220</sup>

Again, unlike the Uniform Act approved by the NCCUSL, Hawaii's modified version of the UHCDA does not provide for the more common approach of a hierarchy of decision makers for

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<sup>217</sup> "Capacity" is an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision. UNIF. HEALTH CARE DECISIONS ACT §1(5), 9 Part IB U.L.A. 89 (2005).

<sup>218</sup> The order prescribed in the UHCDA is as follows:

- (1) the spouse, unless legally separated;
- (2) an adult child;
- (3) a parent; or
- (4) an adult brother or sister.

... (c) If none of the individuals eligible to act as surrogate under subsection (b) is reasonably available, an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, and who is reasonably available may act as surrogate.

UNIF. HEALTH CARE DECISIONS ACT §5, 9 Part IB U.L.A. 111 (2005). This is not the process utilized in all jurisdictions. In Hawaii, for example, there is no listed hierarchy and this "non-designated surrogate" is selected by consensus of "interested persons," essentially those individuals as listed in the UHCDA. *See* HAW. REV. STAT. §327E-5 (1999).

<sup>219</sup> *See* HAW. REV. STAT. § 327E-5 (1999).

<sup>220</sup> *See, e.g.*, the Alberta Province of Canada provisions regarding appointment by a doctor of a decision maker in ADULT GUARDIANSHIP AND TRUSTEESHIP ACT, RSA (2008), c. A-4.2, Part 3 © Alberta Queen's Printer, 2008 <http://www.qp.alberta.ca/documents/Acts/A04P2.pdf>.

a decisionally incapacitated patient, but instead provides for decision making by surrogates selected from a group of “interested persons.”<sup>221</sup>

Under the Hawaii statute, “interested persons” include “the patient’s spouse, unless legally separated or estranged, a reciprocal beneficiary, any adult child, either parent of the patient, an adult sibling or adult grandchild of the patient, or any adult who has exhibited special care and concern for the patient and is familiar with the patient’s personal values.”<sup>222</sup> As explained above, the patient can designate or disqualify a surrogate. Accordingly, interested persons can be “trumped” by an orally designated surrogate. In the same manner, a patient may orally disqualify someone who otherwise might be entitled to make decisions on behalf of the patient.

Hawaii’s version of the UHCDA places restrictions on decisions by “non-designated surrogates.”<sup>223</sup> For example, the statute provides that “artificial nutrition and hydration may be withheld or withdrawn upon a decision by the surrogate only when the primary physician and a second independent physician certify in the patient’s medical records that the provision of artificial nutrition or hydration is merely prolonging the act of dying and that the patient is highly unlikely to have any neurological response in the future.”<sup>224</sup>

Upon a determination that a patient lacks decisional capacity to provide informed consent or refusal for medical treatment, the primary physician or the physician’s designee first needs to make “reasonable efforts to notify the patient of the patient’s lack of capacity.” The primary physician, or the physician’s designee, then must make reasonable efforts to locate as many “interested persons” as practicable. The primary physician may rely on such individuals to notify other family members or interested persons.

Upon locating the interested persons, the primary physician, or the physician’s designee, must inform such persons of the patient’s lack of decisional capacity and that a surrogate decision-maker should be selected for the patient. The interested persons are to make reasonable efforts to reach a consensus as to who among them shall make health care decisions on behalf of the patient. The person selected to act as the patient’s surrogate should be the person who has a close relationship with the patient and who is the most likely to be currently informed of the patient’s wishes regarding health care decisions.<sup>225</sup>

If any of the interested persons disagrees with the selection or the decision of the surrogate, or, if after reasonable efforts the interested persons are unable to reach a consensus as to who should act as the surrogate decision-maker, then any of the interested persons may seek guardianship of the patient by initiating guardianship proceedings. Only interested persons involved in the discussions to choose a surrogate may initiate such proceedings for the patient.<sup>226</sup>

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<sup>221</sup> HAW. REV. STAT. § 327E-5(b) (1999).

<sup>222</sup> HAW. REV. STAT. § 327E-2 (1999).

<sup>223</sup> See HAW. REV. STAT. § 327E-5(e) (1999) (mentions a “surrogate who has not been designated”).

<sup>224</sup> HAW. REV. STAT. § 327E-5 (g) (1999). This particular provision has been the source of some confusion. There are several unanswered questions. Does “any neurological response” equate to something less than brain death and if so, what? Must tube feeding be applied or continued for every patient who has a “non-designated” surrogate selected to make health care decisions if no definition of “any neurological response” can be agreed on by the medical community? Would seeking guardianship rather than selecting a “non-designated” surrogate be an effective means of circumventing the limitations?

<sup>225</sup> HAW. REV. STAT. § 327E-5(d) (1999).

<sup>226</sup> HAW. REV. STAT. § 327E-5(e) (1999).

The law provides that a surrogate designated by the patient may “make health care decisions for the patient that the patient could make on the patient’s own behalf.”<sup>227</sup> In other words, a “designated surrogate” may make all decisions for the patient. The law further states that a surrogate not designated by the patient “may make all health care decisions for the patient that the patient could make on the patient’s own behalf, except that artificial nutrition and hydration may be withheld or withdrawn for a patient upon a decision of the surrogate only when the primary physician and a second independent physician certify in the patient’s medical records that the provision or continuation of artificial nutrition or hydration is merely prolonging the act of dying and the patient is highly unlikely to have any neurological response in the future.” In other words, a “non-designated surrogate” has certain restrictions on making health care decisions about tube feeding.

This particular provision is subject to interpretation and some have claimed that it is unconstitutional as written. This reinforces the notion that an individual should appoint an agent through a health care power of attorney or designate a surrogate if the individual’s wish is to grant another person the power to make health care decisions that the individual could make on his or her own behalf.

Whether the surrogate is “designated” or “non-designated,” a health care decision made by a surrogate for a patient is effective without judicial approval. Further, the supervising health care provider will require a surrogate to provide a written declaration under the penalty of false swearing, stating facts and circumstances reasonably sufficient to establish the claimed authority.

It is important to note that because the constitutionality of the non-designated surrogate provisions under the UHCDA has been questioned, it is even more crucial for an individual in Hawai‘i to consider designating an agent in a health care power of attorney or, at a minimum, designating a surrogate by informing the supervising health care provider.

### **Do Not Resuscitate (DNR) Codes**

Do Not Resuscitate (“DNR”) codes are orders not to provide cardiopulmonary resuscitation (“CPR”) attempts to a person who has stopped breathing or whose heart has stopped beating. There are two basic types of DNRs, “in-hospital” and “out-of-hospital” DNRs. Out-of-hospital DNRs, often referred to as “Comfort Care Only” (“CCO-DNR”) or “Rapid Identification Documents,” will be discussed later in this article.

In-hospital DNRs are placed by a physician with the patient’s (or patient’s legally authorized decision-maker’s) consent in the patient’s treatment chart. A “code” defines the type of medical action to be taken when a patient suffers from a medical distress such as a cardiac or respiratory arrest in a hospital or other health care facility. It is important to know that, in such an emergency, the patient may routinely be resuscitated unless there is a written DNR order in the medical record. This order is sometimes called a “Do Not Attempt Resuscitation” (“DNAR”) or “No Cardiopulmonary Resuscitation” order. The DNR order is only an order to forego the otherwise automatic initiation of CPR and it does not alter other treatment decisions. CPR can include such emergency medical interventions as artificial breathing, chest compressions, cardiac defibrillation (using electric shocks), and certain drugs.

A patient can designate an agent under a health care power of attorney to make such decisions. The decision to refuse CPR may also be made orally by a mentally competent patient to the treating physician. This can also serve as the basis for the DNR order, which is usually signed by the attending physician or supervising health care provider. DNR orders (or “no codes”) are placed

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<sup>227</sup> HAW. REV. STAT. § 327E-5(f) (1999).

in the patient's medical chart and, thereafter, emergency procedures to resuscitate the patient will not be carried out. DNR codes are often written if it is felt that future resuscitation efforts would be futile.

### **Comfort Care Only—DNR Documents and Identification**

Advance healthcare directives under the UHCDA often are not very useful when a patient suffers cardiac or respiratory arrest. In a hospital or other healthcare facility setting, a patient who suffers an arrest is routinely resuscitated, unless there is a written do-not-resuscitate order in the medical record. The DNR order is only an instruction to withhold the otherwise automatic initiation of cardiopulmonary resuscitation and it should not affect other forms of treatment. Outside of a healthcare facility, emergency response personnel normally attempt to resuscitate an individual who suffers a cardiac or respiratory arrest. This may or may not be the course of action that the individual would request if he or she still could make and express a choice. Since 1995, Hawaii law has provided for so-called out-of-hospital do-not-resuscitate protocols.<sup>228</sup>

Under a 2006 statute that modified the 1995 law,<sup>229</sup> the Department of Health was to adopt new rules for emergency medical services which include uniform methods of rapidly identifying an adult person who has certified, or for whom has been certified, in a written "comfort care only" document that the person (or, consistent with the UHCDA, the person's guardian, agent, or surrogate) directs emergency medical services personnel, first responder personnel, and healthcare providers not to administer chest compressions, rescue breathing, electric shocks, or medication, or all of these, given to restart the heart if the person's breathing or heart stops, and directs that the person is to receive care for comfort only, including oxygen, airway suctioning, splinting of fractures, pain medicine, and other measures required for comfort.<sup>230</sup> As of the date this chapter was written, no rules have been adopted but practical information has been provided by the Hawaii Department of Health.<sup>231</sup>

### **Provider Orders for Life Sustaining Treatment (POLST)**

In 2009, the Hawaii Legislature passed a law providing for a health care protocol called Physician Orders for Life-Sustaining Treatment ("POLST").<sup>232</sup> This law was modified in 2014 to include advance practice registered nurses. The POLST form developed under the law, contains information and directions about an individual's end-of-life decisions such as cardiopulmonary resuscitation ("CPR") and tube feeding which emergency medical personnel and other health care professionals are required to follow.<sup>233</sup> By law the POLST form is not an advance directive but a

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<sup>228</sup> See HAW. REV. STAT. § 321-23.6 (2006) (Rapid identification documents).

<sup>229</sup> Act 46 was signed into law amending HAW. REV. STAT. § 321-23.6 on Apr. 27, 2006. See H.B. 3126, 23rd Leg., Reg. Sess. (2006) (enacted).

<sup>230</sup> For specific requirements for the written document containing the certification, see HAW. REV. STAT. § 321-23.6 (2006). Several other states have addressed the issue of out-of-hospital DNRs and, while Hawai'i has taken a unique approach to its statute, several states have similar documents to identify patients who do not want CPR. The documents have varying names but several are called "Physician Orders for Life-Sustaining Treatment" or POLST. See also Robert C. Anderson, *Physician Orders for Life Sustaining Treatment (POLST): Breathing New Life Into End-of-Life Care Planning*, 259 ELDER L. ADVISORY 1 (2012).

<sup>231</sup> See <http://health.hawaii.gov/ems/home/comfort-care-only-do-not-resuscitate-information/>, last visited July 10, 2015.

<sup>232</sup> HAW. REV. STAT. § 327K (2009).

<sup>233</sup> HAW. REV. STAT. § 327K -2(c) (2009).

physician or advanced practice registered nurse's order and, accordingly, is immediately actionable.<sup>234</sup>

Even though it is not an advance directive, the most frequent use of the POLST form is as a summary of an individual's advance directive decisions and information about life-sustaining treatment. The form turns the information and expressed desires into a physician's order that is signed by the physician or advanced practice registered nurse and the individual or his or her health care agent or surrogate. The individual or his or her health care agent or surrogate is encouraged to discuss health care treatment decisions with the primary care doctor and document these decisions on a brightly colored POLST form which is then signed by both the individual and his or her health care agent or surrogate and the doctor. The form is lime green in color, so it can easily be found when needed and because it copies clearly on white paper.<sup>235</sup> A plain white copy, completed correctly, and signed by a doctor is equally legal and valid.<sup>236</sup> Briefly, a POLST contains orders in a standardized form and addresses a range of life sustaining interventions with the patient's preferences for intensity of each intervention. The form is recognized by the Hawai'i Emergency Medical Services System,<sup>237</sup> although it does not replace the Comfort Care Only / Do Not Resuscitate Bracelet/Necklace, it provides immediately actionable directions pertaining to life-sustaining treatment and follows the patient between settings of care, including acute care hospitals, nursing facilities and community settings.<sup>238</sup>

Since the POLST form is not an advance directive and does not name an agent or surrogate, an individual should still consider providing individual instructions and appointing a health care agent through an advance directive. The combination of POLST and advance directive gives an individual the best opportunity to have health care treatment wishes followed. Individuals can ask their doctors about both types of forms.

The major case in the United States addressing rights of patients to make medical treatment decisions and the role of surrogates in making decisions for others was the U.S. Supreme Court case *Cruzan v. Director, Missouri Department of Health* which was decided more than twenty years ago.<sup>239</sup> As you read this case note the arguments to allow substituted judgment. Also note the arguments regarding the level of proof required to evidence a person's wishes. Does the case require that "clear and convincing evidence" be provided?

### **Patient Privacy and Access to Patient Information—The Health Insurance Portability and Accountability Act of 1996 (HIPAA)**

Both state and federal laws impact upon the dual concerns an attorney may have over privacy of an individual's private health care information ("PHI") and access to information on behalf of an incapacitated individual. A federal law, the Health Insurance Portability and Accountability

<sup>234</sup> HAW. REV. STAT. § 327K-1 (2009) ("A provider orders for life-sustaining treatment form is not an advance health-care directive.").

<sup>235</sup> A free copy of the form may be downloaded at Kokua Mau, Hawaii Hospice and Palliative Care Organization, <http://www.kokuamau.org/professionals/polst> (last visited May 25, 2015).

<sup>236</sup> *See id.*

<sup>237</sup> Emergency Medical Services, Hawaii State Dep't of Health, <http://health.hawaii.gov/ems/home/comfort-care-only-do-not-resuscitate-information/>, (last visited May 25, 2015).

<sup>238</sup> KOKUA MAU, A PROVIDER'S GUIDE TO POLST, [http://www.kokuamau.org/sites/default/files/uploads/A\\_Providers\\_Guide\\_to\\_POLST\\_Hawaii.pdf](http://www.kokuamau.org/sites/default/files/uploads/A_Providers_Guide_to_POLST_Hawaii.pdf) (last visited August 24, 2015).

<sup>239</sup> *Cruzan*, 497 U.S. at 261.

Act of 1996 (“HIPAA”),<sup>240</sup> provides strict privacy protections for PHI and requires that “covered entities” such as health plans, health care providers (e.g., hospitals and nursing facilities), or health care clearinghouses verify a person’s identity to ensure that it is the patient or a delegated or authorized “personal representative” who is requesting the patient’s medical records. The HIPAA Privacy Rule provides federal protections for individually identifiable health information held by covered entities and their business associates and gives patients an array of rights with respect to that information. At the same time, the Privacy Rule is balanced so that it permits the disclosure of health information needed for patient care and other important purposes.<sup>241</sup>

Due to the complexity and confusion of the HIPAA statute, individuals who need access to medical records on behalf of an incapacitated patient may have a difficult time gaining access to those records unless they can produce evidence of their authority to receive medical information, including reviewing the medical file, on behalf of the patient. State or other law determines who is authorized to act as a personal representative for purposes of HIPAA. In Hawaii, The Uniform Health Care Decisions Act (Modified) provides that “[u]nless otherwise specified in an advance health-care directive, a person then authorized to make health-care decisions for a patient has the same rights as the patient to request, receive, examine, copy, and consent to the disclosure of medical or any other health-care information.”<sup>242</sup> This would usually include an individual who

- Has been delegated such authority by the patient in writing, or
- Has been appointed by the court to act as guardian, or
- Has been appointed by the patient as an agent in a power of attorney for health care, or
- Has been selected as a “designated surrogate” by consensus of “interested persons,” or
- Has been appointed as a non-designated surrogate acting on behalf of the patient.

For deceased patients, the personal representative or executor of the patient’s estate may qualify. When an individual dies, the personal representative for the deceased is the executor or administrator of the deceased individual’s estate, or the person who is legally authorized by a court or by state law to act on the behalf of the deceased individual or his estate.<sup>243</sup>

A provider or plan may choose not to treat a person as a personal representative if the provider or plan reasonably believes that the person might endanger a patient in situations of domestic violence, abuse, or neglect.<sup>244</sup>

### **Health Care Financing**

This portion of the article is included to provide a very basic overview of health care financing. For a more thorough review, please read the companion article in this volume of the journal.

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<sup>240</sup> The Health Insurance Portability and Accountability Act of 1996 (HIPAA), P.L. No. 104-191, 110 Stat. 1938 (1996).

<sup>241</sup> For a practical overview of this subject see “Understanding Health Information Privacy,” U.S. Department of Health and Human Services, <http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>.

<sup>242</sup> HAW. REV. STAT. § 327E-8.

<sup>243</sup> 45 C.F.R. § 164.502(g). See also

<http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/personalreps.html> (last visited July 14, 2015).

<sup>244</sup> *Id.*

Most persons over sixty-five are Medicare beneficiaries.<sup>245</sup> Medicare can provide some coverage for care in a nursing home but only under limited circumstances and not for extended periods of time. Although most persons over sixty-five are not eligible for Medicaid, due to restrictions on income and assets, it is still advisable to research Medicaid requirements to determine eligibility and alternatives.<sup>246</sup>

Attorneys in this area of law face a changing society and changing legal guidelines. As the role of government benefit programs increases in the lives of greater numbers of moderate-income families, attorneys must be aware of programs and benefits that may impact a person's well-being and wealth. Awareness of these programs widens available financial and estate planning options for clients. This article cannot provide the depth of knowledge that a dementia-capable attorney needs, but it may signal some issues that a lawyer may need to examine in advising an older or incapacitated client, representative or caregiver.<sup>247</sup> Note that, especially with government benefit programs, laws, regulations and policies change often and quickly.

The general population commonly confuses Medicare and Medicaid because of their similar sounding names and the fact that both programs were adopted in 1965. These programs, however, are quite distinct in purpose and tradition, and their journey through history has long been the focus of national debate.

### **Medicare**

Medicare is federal health insurance for people age sixty-five or older, under sixty-five with certain disabilities, and any age with End-Stage Renal Disease (“ESRD”).<sup>248</sup> The Medicare program is run by the CMS of the U.S. Department of Health and Human Services. The original Medicare program that was established in 1965 has two major parts. The two parts, Part A and Part B, continue to this day under the original program and two additional parts, Part C and Part D were added over the years.<sup>249</sup>

People approaching age sixty-five should be aware that they do not need to retire to get Medicare coverage. The law provides for separate applications for retirement and for Medicare. If Medicare becomes too confusing there are some places to go for initial information and assistance.

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<sup>245</sup> MEDICARE PAYMENT ADVISORY COMMISSION, A DATA BOOK, HEALTHCARE SPENDING AND THE MEDICARE PROGRAM ch. 2 (2014) (“In 2010, beneficiaries age sixty-five or older without [end-stage renal disease] composed 83.3 percent of the beneficiary population and accounted for 75 percent of Medicare spending.”)

<sup>246</sup> There are other programs for special populations that an elder law attorney should research depending on the situation of his or her client. For example, "Aid and Attendance" is an underutilized special monthly pension benefit offered by the Veterans Administration for veterans and surviving spouses who require in-home care or live in nursing homes. To qualify, the veteran must have served at least 90 days of active military service, one day of which is during a period of war and must have been discharged under conditions other than dishonorable. Additional information and assistance in applying for the Aid and Attendance benefit may be obtained by calling 1-800-827-1000. Applications may be submitted on-line at <http://vabenefits.vba.va.gov/vonapp/main.asp>. Information is also available on the Internet at [www.va.gov](http://www.va.gov) or from any local veterans service organization.

<sup>247</sup> See, e.g., Medicare and Medicaid chapters of the Hawaii State Bar Association's *Encyclopedia of Estate Planning* which is available through its web site, <http://www.hsba.org>.

<sup>248</sup> See MEDICARE.GOV, <http://www.medicare.gov/> (follow “What is Medicare?”).

<sup>249</sup> *Id.* Part C is not a separate benefit but rather policy that permits private insurance companies to offer special policies to Medicare beneficiaries.

Local Social Security offices have free brochures that explain various parts of Medicare, and Medicare carriers can also be of help.<sup>250</sup>

There are two important rules to remember when Medicare coverage is an issue. First, Medicare only covers care that is "reasonable and necessary" for the diagnosis or treatment of an illness or injury. Care is not considered reasonable or necessary if a doctor places a person in a hospital or skilled nursing facility longer than a person needs to be there. Medicare will end when further inpatient care is no longer reasonable and necessary.<sup>251</sup>

Second, Medicare does not pay for custodial care.<sup>252</sup> This is a vital piece of information for professionals assisting individuals who may face years of institutionalization. Care is considered custodial when it is primarily for the purpose of meeting personal needs and can be provided by persons without professional skills or training. For example, custodial care includes help in walking, getting in and out of bed, bathing, getting dressed, eating, and taking medicine.<sup>253</sup>

All persons age sixty-five and over who are receiving Social Security or Railroad Retirement are automatically enrolled in Part A of Medicare, which primarily covers hospitalization, limited rehabilitation services and limited skilled nursing services in a nursing home.<sup>254</sup> Persons who are over age sixty-five but who are not eligible for either Social Security or Railroad Retirement benefits may nevertheless voluntarily enroll for Part A coverage by paying a monthly premium that is adjusted periodically.<sup>255</sup> Those who purchase Part A coverage must also enroll in Part B and pay the Part B monthly premium that is also adjusted periodically.<sup>256</sup>

<sup>250</sup> See Sage Plus, Executive Office on Aging, <http://www.hawaiihip.org/> (follow "Need help with your Medicare Questions?" for local Social Security Office locations.) (last visited May 25, 2015). The billing office at hospitals or doctors' offices may also help with a claim.

<sup>251</sup> See, e.g., YOUR MEDICARE COVERAGE, MEDICARE.GOV, <http://www.medicare.gov/coverage/pt-and-ot-and-speech-language-pathology.html> (last visited May 25, 2015).

<sup>252</sup> See 42 C.F.R. § 411.404 (2010) ("A beneficiary who receives services that constitute custodial care under § 411.15(g) or that are not reasonable and necessary under § 411.15(k), is considered to have known that the services were not covered if the criteria of paragraphs (b) and (c) of this section are met.") See 42 U.S.C.A. § 1395d (West 2015). See also A GLOSSARY OF TERMS FOR CAREGIVERS, MEDICARE.GOV, <https://www.medicare.gov/files/ask-medicare-types-of-care.pdf> (last visited May 25, 2015).

<sup>253</sup> See 42 U.S.C.A. § 1395d (West 2015). See also A GLOSSARY OF TERMS FOR CAREGIVERS, MEDICARE.GOV, <https://www.medicare.gov/files/ask-medicare-types-of-care.pdf> (last visited May 25, 2015).

<sup>254</sup> 42 U.S.C. § 426(a) (2010).

<sup>255</sup> The Part A premium in 2015 is \$407 per month for individuals who are not otherwise eligible for premium-free hospital insurance.

<sup>256</sup> The Part B premium in 2015 is \$104.90 per month. As directed by the 2003 Medicare law, higher-income beneficiaries will pay higher Part B premiums. See Medicare's Basic Part B Premium to Stay at \$104.90 for 2015, Elder Law Answers, <http://www.elderlawanswers.com/medicares-basic-part-b-premium-to-stay-at-10490-for-2015-14807>. New Medicaid Figures:

- Part B premium: \$104.90/month
- Part B deductible: \$147
- Part A deductible: \$1,260
- Co-payment for hospital stay days 61-90: \$315/day
- Co-payment for hospital stay days 91 and beyond: \$630/day
- Skilled nursing facility co-payment, days 21-100: \$157.50/day
- Higher-income beneficiaries will pay higher Part B premiums. Individuals with annual incomes between \$85,000 and \$107,000 and married couples with annual incomes between \$170,000 and \$214,000 will pay a monthly premium of \$146.90.

Part B is voluntary and covers medically necessary services, such as doctors' services, and supplies that are needed to diagnose or treat a medical condition and that meet accepted standards of medical practice. Medicare Part B covers services (such as lab tests, surgeries, and doctor visits) and supplies (such as wheelchairs and walkers) considered medically necessary to treat a disease or condition.<sup>257</sup>

Hospice services rendered by a Medicare participating program for terminally ill beneficiaries are covered by Part A. The beneficiary's doctor must certify that the beneficiary is terminally ill, i.e., that the beneficiary has a life expectancy of six months or less.<sup>258</sup> A beneficiary who is terminally ill may elect to receive hospice services from a particular hospice program for two ninety-day periods and an unlimited number of subsequent sixty-day periods during the beneficiary's lifetime. A beneficiary who makes this election gives up certain Medicare benefits during the election period.<sup>259</sup> However, he or she may revoke the election at any time during the election period and make a new election.<sup>260</sup> There is a co-insurance charge of five percent of the cost of care for each day plus a minimal charge for drugs. Coverage is for the hospice service only and room and board arrangements may be billed separately.

The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 created a voluntary outpatient prescription drug benefit, known as Medicare Part D that became effective on January 1, 2006.<sup>261</sup> Part D drug plans are approved and regulated by the Medicare program, but are designed and administered by private health insurance companies.

An individual is eligible for Part D benefits if he or she is entitled to benefits under Medicare Part A or enrolled under Part B, and lives in the service area of a Part D plan.<sup>262</sup> Individuals are

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- Individuals with annual incomes between \$107,000 and \$160,000 and married couples with annual incomes between \$214,000 and \$320,000 will pay a monthly premium of \$209.80.
  - Individuals with annual incomes between \$160,000 and \$214,000 and married couples with annual incomes between \$320,000 and \$428,000 will pay a monthly premium of \$272.70.
  - Individuals with annual incomes of \$214,000 or more and married couples with annual incomes of \$428,000 or more will pay a monthly premium of \$335.70 (unchanged).
- Rates differ for beneficiaries who are married but file a separate tax return from their spouse:
- Those with incomes between \$85,000 and \$129,000 will pay a monthly premium of \$272.70.
  - Those with incomes greater than \$129,000 will pay a monthly premium of \$335.70.

The Social Security Administration uses the income reported two years ago to determine a Part B beneficiary's premiums. So the income reported on a beneficiary's 2013 tax return is used to determine whether the beneficiary must pay a higher monthly Part B premium in 2015. Income is calculated by taking a beneficiary's adjusted gross income and adding back in some normally excluded income, such as tax-exempt interest, U.S. savings bond interest used to pay tuition, and certain income from foreign sources. This is called modified adjusted gross income ("MAGI"). If a beneficiary's MAGI decreased significantly in the past two years, she may request that information from more recent years be used to calculate the premium. *Id.*

<sup>257</sup> The Part B deductible for 2015 is: \$147. *See id.*

<sup>258</sup> 42 U.S.C. § 1395x(cc)(3)(A) (2010).

<sup>259</sup> 42 U.S.C. § 1395(d)(1), (2) (2010).

<sup>260</sup> 42 U.S.C. § 1395(d)(2)(B) (2010).

<sup>261</sup> 42 C.F.R. § 423.1 *et seq.* (2010).

<sup>262</sup> 42 C.F.R. § 423.30(a)(1) (2010).

eligible to enroll in a Prescription Drug Plan (“PDP”) if they are eligible for Part D benefits, reside in the PDP’s service area, and are not enrolled in another Part D plan.<sup>263</sup>

### **Medicaid**

Medicaid, on the other hand, is based on financial and other eligibility standards.<sup>264</sup> It is a program designed to help people who have limited income and resources pay for certain health care services. Medicaid is financed jointly with state and federal funds and rules and regulations vary from state to state. Due to this partnership, the Medicaid program is subject to both federal regulations and state statutes. Hawaii’s Medicaid program is administered by the Med-QUEST Division of the Department of Human Services under Hawaii Administrative Rules Title 17, Subtitle 12.

Medicaid is the payer of last resort. All other medical coverage, which an individual has from third parties, must be the primary payer of an individual’s medical expenses. Medicaid will only cover the portion of the costs in which another insurance (Medicare, for example) does not pay. Individuals who qualify for fully subsidized Medicaid generally are not responsible to share in the cost of Medicaid covered services.

Individuals who apply for Medicaid must meet basic, categorical, and financial eligibility requirements to receive medical assistance. The basic eligibility requirements encompass residency, identification, and citizenship or alien status. Categorical eligibility requirements determine which managed care program an eligible individual will receive benefits under, and how an individual’s income and assets are considered in determining the financial eligibility. There are several “types” of benefit programs, but most people with dementia would qualify through the “Aged, blind and disabled” program. Only the assets and income of responsible family members are used to determine an individual’s Medicaid eligibility. For Medicaid purposes, responsibility for support is from spouse to spouse, and from natural parents to their minor children.

### **Transfer of Assets Penalties**

The transfer of any assets (other than the couple’s home, under certain circumstances) for less than fair market value for the purpose of qualifying for Medicaid can result in a penalty period or period of ineligibility. Some other transfers are also exempt, including cash to a spouse or funds to people with disabilities. Currently, transfer of asset penalties only apply to the long-term care benefit program. There are no transfer penalties for other Medicaid programs. However, transfers to certain family members are exempt from the disqualification rules. If the transferred resource is the applicant’s home, there is no disqualification for transferring title to the following if they are lawfully residing in the home:

- (A) the spouse of such individual,
- (B) such individual’s child who is under age 21, or (with respect to States eligible to participate in the State program established under subchapter XVI of this chapter) is blind or permanently and totally disabled, or (with respect to States which are not eligible to participate in such program) is blind or disabled as defined in section 1382c of this title, or

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<sup>263</sup> 42 C.F.R. § 423.30(a)(2) (2010).

<sup>264</sup> Medicare is authorized under Title XVIII of the Social Security Act, and Medicaid is authorized under Title XIX of the Social Security Act.

(C) a sibling of such individual (who has an equity interest in such home and who was residing in such individual's home for a period of at least one year immediately before the date of the individual's admission to the medical institution).<sup>265</sup>

There are other rules which provide for the transfer into a special needs trust to the individual's child who is under age twenty-one or a blind or disabled child, or to an individual who is under age sixty-five and who is disabled, but this transfer exclusion does not relate to the home.<sup>266</sup>

The Deficit Reduction Act of 2005 addressed many of the loopholes, which individuals or their representatives have exploited in Medicaid rules to transfer certain assets without incurring a penalty. A penalty period in which Medicaid will not provide long-term care coverage will be assessed if the individual or the individual's spouse transferred an asset for less than fair market value within the applicable look-back period prior to the request for long-term care coverage. The look-back period is thirty-six months for an asset transferred prior to February 8, 2006, sixty months for an asset transferred on or after February 8, 2006, or sixty months for an asset transferred to an irrevocable trust prior to February 8, 2006.<sup>267</sup>

A penalty period will not be assessed when: the asset transferred was the individual's home and title to the individual's spouse, child under age twenty-one or a blind or disabled child, a sibling who has equity interest in the home and has lived in the home at least one year immediately before the individual requested Medicaid payment of long-term care services, or an adult child who has lived in the home for at least two years immediately before the individual became institutionalized and was a caregiver to the individual. The asset, other than a home, was transferred: to the individual's child who is under age twenty-one or who is a blind or disabled child, to a trust established solely for the benefit of an individual's community spouse, from the community spouse to another for the sole benefit of the community spouse, to an individual under age sixty-five and who is disabled. However, the individual can verify that he or she intended to transfer the asset at fair market value or for other valuable consideration, that the asset was transferred solely for a purpose other than to qualify for Medicaid, or that the asset was returned.<sup>268</sup>

Individuals with more than \$828,000 (2015) of equity in their home are ineligible for long-term care services Medicaid coverage, unless the individual's spouse or dependent child lives in the home. Individuals may reduce their equity in the home through a reverse mortgage or home equity loan without penalty, and an individual has the right to file for a waiver if he or she cannot legally reduce their home equity.<sup>269</sup>

The period of ineligibility is the value of the transferred asset, divided by the monthly statewide average cost of private care in a long-term facility (currently \$8,500). The department may waive the penalty period if it determines that imposing the penalty would cause undue hardship for the individual.<sup>270</sup>

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<sup>265</sup> 42 U.S.C.A. § 1396p.

<sup>266</sup> *See, e.g.* 42 U.S.C.A. § 1396p(c)(2)(B). HAR 17-1725.1-56 exempts a transfer of the home to a disabled child but not to a trust for such child. The asset other than a home may be transferred to the special needs trust.

<sup>267</sup> 42 U.S.C.A. § 1396p(c)(1)(B).

<sup>268</sup> 42 U.S.C.A. § 1396p(c)(2)(C). Anecdotal evidence suggests that some intake workers in Hawaii have interpreted this caregiver requirement to mean that the child was performing nursing level services.

<sup>269</sup> *See* ELDER LAW ANSWERS, FIVE MYTHS ABOUT MEDICARE'S LONG-TERM COVERAGE, No.2, <http://www.elderlawanswers.com/five-myths-about-medicaids-long-term-care-coverage-12114> (last visited May 25, 2015).

<sup>270</sup> 42 U.S.C.A. § 1396p(c)(1)(E).

The beginning date for the period of ineligibility is the first day of a month during or after which assets have been transferred for less than fair market value, or the date on which the individual is eligible for medical assistance under the State plan and would otherwise be receiving institutional level care based on an approved application for such care but for the application of the penalty period, whichever is later, and which does not occur during any other period of ineligibility.

A question that is often asked is “What happens when the institutionalized spouse receives an inheritance after eligibility?” Current Medicaid rules do not allow disclaiming an inheritance.<sup>271</sup> A Medicaid recipient cannot simply disclaim the inheritance in favor of other heirs because Medicaid views this as a transfer of assets to those heirs. The Medicaid recipient is deemed to have received the inheritance and then to have given it away.<sup>272</sup> When transferring assets out to achieve Medicaid eligibility, the look-back period is five years. In other words, a person who transfers assets during the look-back period must wait out the penalty period. As mentioned above, the period of ineligibility is the value of the transferred asset, divided by the monthly statewide average cost of private care in a long-term facility (currently \$8,500).

### Spousal Impoverishment Provisions

The Medicare Catastrophic Coverage Act (“MCCA”) protects against “spousal impoverishment” by setting special income and resource rules for married couples when one spouse is placed in a long-term care facility and the other spouse remains in the community.<sup>273</sup> Prior to the MCCA, in order to qualify for Medicaid payment for the care for the institutionalized spouse, the couple had to reduce their assets to Medicaid asset allowance and the community spouse could only receive financial support from the institutionalized spouse up to the Medicaid income standards.<sup>274</sup>

Congress amended the Social Security Act to ensure that the MCCA provisions comply with the Affordable Care Act by adding section 1924, which affected the treatment of the married couple's assets and income in determining the Medicaid eligibility of the spouse who needed assistance to pay for long-term care in a nursing home or other medical facility.<sup>275</sup>

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<sup>271</sup> See ELDER LAW ANSWERS, WHAT HAPPENS TO A MEDICAID RECIPIENT IF THE COMMUNITY SPOUSE DIES FIRST?, <http://www.elderlawanswers.com/what-happens-to-a-medicaid-recipient-if-the-community-spouse-dies-first-14861> (last visited May 25, 2015). See also Adam J. Hirsch, *Disclaimers and Federalism*, 67 VAND. L. REV. 1871, 1896 (2014).

<sup>272</sup> A gift in a will is *not* a transfer.

<sup>273</sup> 42 U.S.C.A. § 1396r-5(c)(2).

<sup>274</sup> Elizabeth D. Lauzon, Annotation, Application of “Spousal Impoverishment Provisions” of Medicare Catastrophic Coverage Act (42 U.S.C.A. § 1396r-5), 186 A.L.R. FED. 437 (2003).

<sup>275</sup> Centers for Medicare and Medicaid Services, Affordable Care Act’s Amendments to the Spousal Impoverishment Statute Guidance letter, SMD#15-001 (May 7, 2015) available at <http://medicaid.gov/federal-policy-guidance/downloads/smd050715.pdf>. The Affordable Care Act amended section 1924(h)(1) to *require*, for the five-year period beginning January 1, 2014, that states include in the definition of an “institutionalized spouse” married individuals who are “eligible for medical assistance for home and community-based services provided under subsection (c), (d), or (i) of section 1915, under a waiver approved under section 1115, or who [are] eligible for such medical assistance by reason of being determined eligible under section 1902(a)(10)(C) or by reason of section 1902(f) or otherwise on the basis of a reduction of income based on costs incurred for medical or other remedial care, or who is eligible for medical assistance for home and community-based attendant services and supports under section 1915(k). . . .”

The new definition eliminates the discrete reference to the 217 category and applies to all married individuals eligible for home and community-based services (HCBS) delivered through 1915(c) waivers, 1915(i) or (k) state plan benefits, or section 1115 waivers who are married to a spouse who is not in a medical

Only the income of the institutionalized spouse will be considered to determine Medicaid eligibility and the community spouse may receive allowances to retain portions of the couple's assets and a portion of the institutionalized spouse's income. Federal regulations set a minimum and a maximum amount for the asset and income allowances, and allow the states to establish the amount of the allowances. The allowances are subject to increases via indexing, court orders or fair hearing decrees. Hawai'i chose to use the maximum amount for both asset and income allowances.

In the month the Medicaid application for the institutionalized spouse is filed, all non-exempt assets owned by a couple are evaluated and totaled. The community spouse is allowed to retain an amount allowed by law. The 2015 amount is \$119,220. Once Medicaid eligibility is established, assets owned by the institutional spouse may be transferred to the community spouse during a "protective period" of ninety days, which may be extended because of legal reasons or certain circumstances that delay the transfer.<sup>276</sup> Any assets still legally available to the institutionalized spouse after this period will be considered in determining the continued eligibility of the institutionalized spouse.<sup>277</sup> After Medicaid eligibility is established, the assets owned by the community spouse where the institutionalized spouse is not a co-owner will not affect the continued eligibility of the institutionalized spouse.<sup>278</sup>

Under the provisions of the MCCA, the income of the community spouse is not considered available to the institutionalized spouse.<sup>279</sup> If income from non-trust property is in the name of both spouses, then one-half of the amounts will be considered available to each spouse.<sup>280</sup> The new monthly maintenance allowance is based on the difference between the maximum income allowance (\$2,980 in 2015) and the gross income of the community spouse. If the institutionalized spouse agrees, the income of the community spouse can be supplemented by a contribution from the institutionalized spouse up to the amount of the monthly maintenance allowance.

### Recovery of Medicaid Funds

Under the provisions of OBRA 1993,<sup>281</sup> states were required to establish Medicaid recovery programs, which included mandatory recovery of medical assistance payments for nursing home care. Hawaii will seek recovery of Medicaid payments from the estates of deceased individuals who received assistance while in a nursing facility or other medical institution at any age, and from individuals not in nursing facilities who received benefits from age fifty-five.<sup>282</sup> Recovery will not be pursued if the deceased recipient had a surviving spouse or surviving dependent child. Recovery of medical assistance paid in error due to the complicity of an individual are made directly from the individual or the individual's estate.

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institution or nursing facility. Also included are those who qualify through a spend down, either as medically needy or categorically needy in a 209(b) state. This expanded definition (hereafter "new definition") means that states must apply the spousal rules to Medicaid applicants who historically have not had their eligibility determined under these rules.

<sup>276</sup> See ElderLawAnswers, Key Medicaid Information for Hawaii for 2015, <http://www.elderlawanswers.com/key-medicaid-information-for-hawaii-for-2015-12174> (last visited May 25, 2015).

<sup>277</sup> *Id.*

<sup>278</sup> *Id.*

<sup>279</sup> 42 U.S.C. § 1396r-5 (2010).

<sup>280</sup> *Id.*

<sup>281</sup> The Omnibus Budget Reconciliation Act of 1993 Pub.L. 103-66, 107 Stat. 312, enacted August 10, 1993.

<sup>282</sup> HAW. REV. STAT. § 346-37 (2010).