



Deciding To Navigate Elder Care

**A Legal Handbook for Hawai‘i’s
Older Persons, Families and Caregivers**

By James H. Pietsch, JD and Lenora H. Lee, PhD

University of Hawai‘i Elder Law Program

William S. Richardson School of Law



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*Printed under a grant from
the Hawai'i Justice Foundation*

2022

PREFACE



Chances Are you will be a caregiver or care recipient, and, in some instances, maybe both. You will need to be able to address a plethora of elder care issues, such as health care, financial and legal issues. This publication is an introductory caregiver’s guide with a legal emphasis and will help you to navigate elder law in Hawaii.

In this publication, we list guidelines in planning for the future, including planning ahead for possible future incapacity, how to manage the plethora of health care rules and how to make good legal and financial decisions and most important how to hire a caregiver. We also describe when and how to find a “dementia-capable” lawyer, and lastly, what to do upon the death of a care recipient.

For more details and a broader discussion about these life issues, see UHELP’s legal handbook *Deciding What to Do and Why Not Now?— A Legal Handbook for Hawai’i’s Older Persons, Families and Caregivers*, which is available online at <http://hawaii.edu/uhelp/handbook.htm>

As future editions are published, they will be included on the website. AARP has an excellent website at <https://aarp.org/caregiving> which provides information and resources pertaining to the vast array of caregiving issues in elder care, including self-care, becoming a “sudden” caregiver, and improving the lives of caregivers. Use the AARP resource in tandem with this Hawai’i-focused handbook to get the most about navigating elder care.

The University of Hawai'i Elder Law Program is grateful to the Hawai'i Justice Foundation, which provides access to justice for Hawai'i's people and makes possible this project. We, at the William S. Richardson School of Law, in providing legal services to older persons and caregivers for over thirty years, wish to thank all our *kūpuna* and families.

We hope that this book will give you information and ideas that will help you in your role as a caregiver or a care recipient in the complex area of elder care.

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Caution: This handbook book contains basic information to help you get started on navigating elder care in Hawai'i. While it provides practical and helpful information, it is not intended to serve as a “do-it-yourself” legal guide or as a substitute for professional legal advice. If you have legal questions, you should seek the advice of an attorney.

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CHAPTER 1

PLANNING AHEAD FOR A LIFETIME



When we wrote our first book at the University of Hawai'i Elder Law Program (UHELP), *The Elder Law Hawai'i Handbook*, life seemed simpler as we centered our attention on basic legal needs of older adults. Our motto was to “prepare for the worst so you can enjoy the best.” The Covid-19 pandemic challenged this basic assumption as few could predict the devastation that the disease and social isolation has had, especially among older persons.

We suggested that if our clients who were older adults had not started planning for longevity and the rest of their lives, they should start planning right away. To those who did not know where and how to start, we suggested that they begin by thinking about and answering some basic questions:

- Where will you live?
- What will you do for income?
- What will you do with your time?
- Who will care for you? and,
- What really matters to you?

While we at UHELP still advise older adults to start with that simple formula, we now caution them that answers to these basic questions have grown more complicated; laws may have changed as well as their lives and lifestyles. For

potential caregivers, the thought of navigating elder care issues to meet the needs and requirements of older persons at various stages of aging may be daunting. The stages of elder care may progress from informal support and advice, to home care, adult daycare, assisted living, long-term care, nursing home care and perhaps at the end, hospice care. If a potential caregiver thinks through how they may wish to have their own care provided when they get older, it may become a bit easier to plan, especially if they understand some basic legal, financial and health care issues that may be involved in elder care.

For example, the answer to “Who will take care of you?,” might mean buying long-term care insurance rather than counting on family members to provide care. Aging in place may not be possible because of your reduced income or family dynamics or the vagaries of life, even though it is a much desired way to spend the rest of your life. Further, there are different laws that affect older adults more than younger adults: Social Security and Medicare are two examples.

Demographics have also changed. Many “baby boomers” have already joined the “silver tsunami” and, perhaps, some of their friends and family have lived to be a hundred years old. Longevity has affected lifestyles, how persons live, where they live, their income or lack of income and even those who will care for them when loved ones become incapacitated or die. Planning ahead has become more urgent and complicated as evidenced by the effect the Covid-19 pandemic has had on the whole world and especially on older persons. To update plans for the best possible future, we suggest adding several more areas to the “to-do list” of preparing for the worst:

- Prepare for the possibility of diminished or lack of mental capacity. Dementia may make you more vulnerable to elder abuse, neglect and exploitation. The older you are, the more chance you will have of being affected by dementia.
- Prepare for possible assisted living if you need help to get around or take care of yourself. It would be ideal to age in place and stay in your own home and community, but it may not be possible.
- Save more money or at least know what benefits are available, because the cost of care, and especially long-term care, is very expensive. Even if you have children, you may or may not be able to count on them to help. Moreover, you will need to be money savvy and take steps to

lessen your vulnerability to financial exploitation.

- Take care of yourself and do not assume that your children might take care of you. You might find yourself taking care of their children as well as yourself.

We urge older persons to talk to family, caregivers, potential caregivers and health care providers about what matters to them and what their wishes may be regarding their money and home, medical treatment and the future. They can decide what matters to them and express their desires and thoughts in a legally recognizable manner by having the following documents prepared:

What Matters to Me . . .

- A will,
- A power of attorney,
- An advance health care directive,
- A trust, especially for any real property or other significant assets I might own,
- A POLST (Provider Orders for Life-Sustaining Treatment) form,
- A Written Instrument to Control Disposition of Remains; and,
- A personal “What Matters to Me” document about their wishes and values.

In the following chapters, we explain how these documents help to pinpoint what matters to an individual, especially to an older individual.

The theme and intention of these documents are to use them to “plan for a lifetime” by considering personal, legal, financial, social, and health care needs. We hope that these plans and legal documents will minimize the vagaries of life, those unexpected and unwelcome turns of fortune and mislaid plans. And most important, let family and, of course caregivers, know what matters the most to them.

In this book we will describe how “dementia capable” attorneys and other professionals are trained to recognize and address the signs of dementia and other related problems. We will provide an overview of what a “dementia capable” professional, trained caregiver or family caregiver should know in “deciding what’s important.”

There are repeated warnings in this book about elder abuse. Unfortunately, family members continue to be the most common perpetrators of abuse, including financial exploitation. Interspersed throughout this book, you will get the sense that being too trusting could endanger your own independence and autonomy. This is especially significant due to new laws that empower agents and others to do many things, including potentially changing the intentions you had when you signed your legal documents.

The requirements for Medicaid and the rules of long-term care are provided in a condensed manner in this book. For the latest UHELP handbook and additional information, visit <http://hawaii.edu/uhelp/handbook.htm>

There you will find information on health care financing, the difference between Medicare and Medicaid and current eligibility standards. Perhaps the best “advice” for living and enjoying longevity is simple and personal:

- Remember the golden rule – treat others as you wish to be treated.
- Be kind to yourself as we all make mistakes.
- Maintain friendships or make new friends to avoid being isolated.
- Maintain or learn a skill to keep your mind active and have something to do even if you become less physically active.

CONTEMPORARY PLANNING ISSUES FOR OLDER PERSONS AND CAREGIVERS

This book is designed around a “planning for a lifetime” approach that takes into consideration personal, legal, financial, social, and health care needs. The Covid-19 pandemic has demonstrated that it is almost impossible to predict the future—who knew that the pandemic would have such a devastating and long-lasting effect on the entire world? While you plan for the future and prepare for the unexpected, here are some contemporary issues that you might not have thought about but that can be troubling and surprising when they pop up.

Marriages, Reciprocal Beneficiaries, Domestic Partnerships

You should be mindful that both state and federal laws will impact various aspects of your “planning for a lifetime” and perhaps your relationships with

others. Federal recognition of same-sex marriages provided federal protection or benefits to individuals enrolled in federal programs such as Medicaid, Medicare and Social Security and veterans' benefits. The Hawai'i Marriage Equality Act legalized same-sex marriage in 2013 and allowed same-sex couples to marry. Couples in this relationship have all the legal rights, benefits, protections and responsibilities of traditional marriage such as the ability to file joint tax returns, to enjoy inheritance rights and to make hospital and prison visitations.

Hawai'i also has an older law, the Reciprocal Beneficiary Law, that was passed prior to the Hawai'i Marriage Equality Act. Those in a reciprocal beneficiary relationship are prohibited from marriage, for example, to first cousins, or prior to 2013, same-sex couples. They must register as reciprocal beneficiaries to share in Hawai'i's marital benefits and privileges, such as having access to Hawai'i's inheritance laws, holding property as tenants by the entirety, and having hospital and jail visitation rights. However, unlike same-sex marriage, these couples may not share in the same federal benefits because they cannot or could not marry; for example, they cannot file a joint tax return unless they marry.

Another contemporary law concerns domestic partnerships which are recognized in Hawai'i and among a small number of other states. In a domestic partnership, two people live together and are involved in a romantic or interpersonal relationship but are not legally married. They can share certain benefits such as employee health benefits, bereavement leave and visitation rights in hospitals and jail. However, they may not be entitled to make health care decisions, funeral arrangements, or claim any part of their partner's estate or social security benefits. Currently, although some employers include domestic partners in their list of benefits, there are no federal or state laws that require employers to include domestic partners in their benefit plans.

Although Hawai'i recognizes domestic partnerships, it does not recognize common-law marriages. One of the misconceptions is that if you and your partner have lived together for 7 years (or some other designated period), you are considered to be in a common-law marriage. This is not true in Hawai'i although it may be true in some other states. If a "common-law spouse" who is not recognized in Hawai'i as married, dies without a will or does not adequately provide for the other common-law spouse in a will, there is no automatic right to an inheritance or to property and bank accounts unless that other common-

law spouse is on title. Often, many older adults who assumed that they would inherit or be taken care of when their partner died are left with a broken heart when their partner's family rejects them and prevents their attempts to visit their partner in a health care facility or to have access to funds. Often, they are the ones who nursed and cared for their partners when the family was too busy or unavailable to lend a hand.

Marriage and relationship laws may continue to change. If you have a question about same-sex marriages, reciprocal beneficiaries, domestic partnerships or common-law marriages in Hawai'i you may wish to contact a local family law attorney for assistance. These various relationships may impact other areas such as inheritance, taxes and estate planning.

Real ID Act

Another important legal development that still concerns older persons and caregivers is the REAL ID Act, passed by Congress in 2005 and implemented by the 9/11 Commission's recommendation that the federal government "set standards for the issuance of sources of identification, such as driver's licenses." REAL IDs will be necessary for travelers within the United States by May 3, 2023. Your driver's license or state identification will need to be REAL ID-compliant if you want to use it to fly within the U.S. If your license or state ID is not compliant, and you don't have another acceptable form of identification, such as a valid passport, you will have trouble getting through airport security.

Proving identity for some people can be difficult, because of name changes, particularly for older married or divorced women and those with out-of-state marriages.

These standards can make it complicated, if not nearly impossible, for some people to renew their licenses or state IDs, especially if the identification is in question. It is not unusual for an individual to be denied boarding for air travel and even for benefits, including health care benefits for not having a "federally compliant" identification document. Very often complications arise when people lose their birth certificates or use different names from those indicated on their birth certificates. Now, to get a new ID, an applicant needs to demonstrate "name traceability," that is, a connection between the name presented on the source document and the name requested to be on the issued document. To

further complicate the matter, sometimes when individuals have been forced to legally change their names to comply with the REAL ID Act, their previously executed documents may no longer be accepted as valid.

To apply for a Hawai'i State Identification Card for the first time, you must apply in person and provide documentary proof of legal name, date of birth, social security number, legal presence and Hawai'i principal residence address. A photograph must also be taken. Full names on all documents must be the same or you must provide "connecting documents" to establish the link between the names of any documents that have different names. To view and print the "List of Acceptable Connecting Documents to Prove Legal Name Changes" document guide, visit: <https://hidot.hawaii.gov/hawaiistateid/>

If you need a Social Security card, visit: <http://www.socialsecurity.gov/ssnumber/ss5doc.htm>

If you do not believe that things could get worse for these individuals, consider what may happen when it is the caregiver who is applying on behalf of an individual who is no longer mentally capacitated and whose ID has expired, and the caregiver has little information about where important documents may be found. The *Kōkua* Packet at the end of the handbook on the UHELP website at <https://hawaii.edu/uhelp/handbook.htm> can be a valuable tool.

Disappointment in Life and "Proxy" Decision-Makers

Frailty, illness, mental incapacity, fear, language barriers, and poverty are just a few of the reasons some older persons are unable to manage their own affairs and may need the assistance of a caregiver. They may need someone to take care of them, but many have no one to help. To make matters worse, some older persons are being abused, neglected, or exploited by strangers, acquaintances, and even family members. For a large number of older adults, the Covid-19 pandemic resulted in extended "lockdowns," which imposed severe restrictions on person-to-person contact, resulting in long periods of isolation from families and friends. An older adult who is isolated may be more at risk for elder abuse.

Too many times older persons are disappointed at the end of their lives. Some thought they had planned well. Others did not do much planning at all. Many

were hoping for the best but got the worst. One just has to read the newspaper or watch the news to see examples of high-profile cases in which matters seemed to have turned out badly for an older person. These cases include fights over an older person's desire for autonomy and self-determination, over one's own property decisions, allegations of fraud, theft or at least improper use of an older person's assets, and efforts to override the older person's medical choices at the end of life.

Just as often, it seems, entire families are disrupted by conflicts involving the care of an older person at the end of life or by manipulative family members scheming to get the older person's assets before death or vying to gain a larger inheritance. Very often lawyers are involved, too, whether they represent the older person, the family member or caregiver or, maybe, themselves.

We will provide an overview of some of the Hawai'i statutes that are commonly applicable to proxy (substituted or legally authorized) decision-making on behalf of a person who lacks capacity, or who may have limited capacity, or who may be unable to make decisions, or unable to make critical decisions on a timely basis. We will also clarify what the term "surrogate" specifically means under Hawai'i's health care decisions law.

For the most part, individuals who act as proxy decision-makers are trustworthy. Although both they and the person for whom they are making decisions are acting in good faith, proxy decision-making is often done in private without any oversight. Adding to the difficulty of monitoring and overseeing whether decisions are made to benefit the incapacitated person, laws may often be inconsistent. This may result in having provisions in some statutes that appear to protect but may inadvertently give the proxy decision-maker the power to make decisions that may not necessarily be in the best interest of the incapacitated person or may prove to be self-serving.

Accordingly, be aware of high expenses and fees that proxies might charge, but also be mindful when someone decides to withhold treatment or services or resources too quickly to "spare grandpa or grandma from suffering too long." Always ask for an accounting from proxies and, most of all, ask yourself what your loved one or person you care about would have wanted.

PLANNING FOR INCAPACITY

There are two important ethical considerations attorneys must address when dealing with older clients and with their health care providers, financial advisors, family members and caregivers:

- Who is (or will be) the client? and, when the identity of the client is clear,
- Is the client (or potential client) competent (does the client have sufficient mental capacity) to make decisions?

Family members may try to talk for their parents or relatives. And the conversation may turn to what they might want to see happen which might not be what the parent wants. Sometimes the conversation becomes overwhelming when there are different opinions in the “best interest” of the elder person concerned.

Family conflicts can happen when an adult child takes advantage of a parent’s diminished capacity; for instance, when the adult child asks a parent to sign a legal document such as a power of attorney, that gives that child power over personal, legal and financial matters concerning the parent and leaves out other family members. Often who pays the attorney’s fees influences how the legal document is structured.

Be aware that in addition to family, cultural practices may influence a person’s decisions. In Hawai’i, as well as in various other parts of the nation, culture may affect autonomy and independence in decision-making. Yielding to a spouse’s, child’s or clan leader’s wishes may be reflected in a number of decisions such as wills, health care, and even end of life.

To guard against the possible breach of confidentiality, the lawyer or health care provider must always be able to identify who the client is and to whom allegiance must be given. Some would propose that “the family” is the client but the ethical responsibility would still require a determination of the identity of the client.

Elder law attorneys and health care providers sometimes face enormous pressure to breach the confidentiality of their older clients or patients, who may not be very “sharp” or who depend heavily upon another person. Spouses, health care providers, hospitals and nursing homes, caregivers, and others

may overlook the need for confidentiality and privacy. To guard against the possible breach of confidentiality, a lawyer or health care provider must always define who the client is and to whom allegiance is owed. If they can answer, “Who is the client?” and “Is the (potential) client mentally capacitated and free from undue influence?,” they may be able to cut through the noise and confusion when families bring their older members to see the provider. Lawyers will usually need to meet with the client or potential client in private.

The following information may help you determine whether the client or potential client has capacity.

INCAPACITY, MEMORY LOSS AND DEMENTIA (NEUROCOGNITIVE DISORDER)

Mental incapacity or serious memory loss can affect activities of daily living, safety, the ability to live independently, to make personal choices or to execute valid legal documents that may affect a person’s life. The law recognizes that adults (usually persons over age 18), have the right to manage their own affairs, conduct business, and among other things, to make their own health care decisions. Although an adult is presumed to be “competent” or “capacitated,” it is a “rebuttable” presumption. In working with clients, the question often arises as to whether the individual has the “capacity” to make decisions. Judicial declarations of “incompetency” and “incapacity” are infrequent but may be required under certain circumstances.

The concept of capacity, or incapacity, is more activity specific than the concept of competency or incompetency, which often has a more global connotation. The most common court cases where capacity is an issue involve guardianship, conservatorship, adult protective services, and civil commitment. To be considered legally valid, each decisional activity (e.g., provision of informed consent for medical treatment, execution of a will, making gifts, completion of an advance health care directive, etc.) may require a different level of decisional capacity. These are areas in which doctors and lawyers often work together to help assess an individual’s ability to make decisions.

Various studies have shown that there is a significant decline in “financial literacy” in older persons, not necessarily related to dementia. This decline

starts slowly, usually around the age of 60 and the rate of decline increases with age. Paradoxically, overconfidence about financial decision-making seems to increase with advancing age. This may explain why older persons may seem to make more mistakes regarding their finances as they grow older, and they may not even realize that they are making mistakes. This is similar to the phenomenon of reduced driving skills among many older persons. Studies have shown that older drivers may not be aware that their driving skills have declined even though they should know that their cognition, reflexes, eyesight and hearing decline with advancing age.

One of the least understood conditions that gives rise to questions of competency or capacity is dementia, a decline in mental ability. Alzheimer's, the most common cause of dementia, is a specific disease and dementia is not. Dementia is a term many people fear to hear. As a matter of fact, in order to address the negative response that the term, "dementia," may evoke, the American Psychiatric Association is essentially attempting to replace the term, "dementia," in favor of the term, "neurocognitive disorder," and for cases with clinical significance, "major neurocognitive disorder." The term, "dementia," will be used for simplicity in this book.

If the condition is discovered and addressed early enough, it may be possible to make informed and reasoned decisions and to set appropriate legal mechanisms in place for the future. Writing a "values history" or noting what matters to the individual is often a good idea and many families are able to guide their loved ones to make decisions and take action to preserve as much of their personal independence and well-being as possible.

There is a difference between memory loss and dementia. You can have short-term memory loss but not have dementia. For example, a person who occasionally asks, "Where did I put those keys?" would probably not be considered to have dementia. 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. Dementia may be reversible or irreversible and progressive. Depending on its stage, 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 may also have an effect on a person's personality, behavior or attention span.

Memory loss is a problem that many older persons (as well as many younger persons) worry about. However, having memory loss does not necessarily mean that you lose the capacity to make decisions. The aging process can have an effect on memory by changing how the brain stores and recalls information. As one ages, brain chemistry changes and brain cells die and are never replaced. Since the older brain has fewer brain cells and stores information differently from a younger brain, memory loss is not unusual. As one ages, it often becomes more difficult to recall stored information, especially newly stored information. This is why individuals may often be able to remember events from long ago with great clarity but may fail to remember more recent events such as the introduction of people they have just met.

In addition to dementia, memory loss can be caused by other things such as poor nutrition, the side effects from head injuries, heart attacks, strokes, alcohol consumption, depression, disease, or illness. Drugs, including chemotherapy, anesthesia, and anti-depressants as well as other medical treatments can also lead to memory loss.

Memory loss can be a serious problem if it affects a person's daily living and decision-making capability. Most people can learn to cope with memory loss (and sometimes, the associated confusion) by keeping busy, making lists, following a daily routine, including exercising (with a doctor's approval), putting objects (such as keys) in the same place, and by keeping healthy (including eating nutritious foods and especially vegetables), and maybe by not worrying too much about forgetting things. A doctor, and especially a geriatrician, can also suggest how to keep the body and brain functioning at optimum levels.

While there are different types of dementia depending on the cause, Alzheimer's disease is the most commonly dreaded form and can place a great burden on the patient and on caregivers. Alzheimer's is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks. Although it seems that current Alzheimer's treatments cannot stop it from progressing, they can temporarily slow the worsening of symptoms and improve quality of life for those with the disease and their caregivers.

Decisional Capacity

An individual is usually considered to have decisional capacity when the individual is sufficiently able to receive, understand, and evaluate information and to communicate a particular choice. This means, minimally, that the individual has the ability to understand the nature of the problem or activity the individual is facing, to understand available alternative courses of action (including no action), to understand the possible risks and benefits attached to each alternative, and that the individual is able to express a choice. Note that issues associated with decisional capacity are different from issues associated with “undue influence,” which can be exerted by one person over another person. The more difficult cases involve situations where an individual may be experiencing diminished capacity and may also be subjected to the undue influence of another person to do or not to do something.

Whether a person is considered to have decisional capacity depends on each specific situation. For example, a judge may declare a person legally incapacitated to manage the person’s own affairs and may appoint a guardian or conservator for that person. However, that person may still be deemed to have sufficient mental capacity to execute a will. Conversely, while that person has the capacity to execute a will, the person may not have the mental capacity to enter into a contract.

CHAPTER 2

GUARDIANSHIP, CONSERVATORSHIP AND ALTERNATIVES TO GUARDIANSHIP



We discuss guardianship and conservatorship in this handbook since you should know about the legal procedures you may have to go through if an individual does not plan ahead effectively for incapacity. Often families are conflicted when a family member cannot self-care or is resistant to accept help. Sometimes it is possible for another family member to assume the responsibility of caring, paying bills, and making other medical and financial decisions for that individual. In other instances, when effective alternatives such as a power of attorney, have not been set up, it may be necessary or appropriate to seek a guardianship or a conservatorship.

It is easy to be confused about guardianships and conservatorships. Guardianships are court proceedings where someone, a “guardian,” is appointed by a court to protect the interests of another person who may be unable to care for themselves. Guardians are involved in decisions about a person’s living arrangements, unlike conservators, who are involved in decisions about a person’s property, including finances. Guardians can decide where the ward is to live, who can visit, what the ward eats, what medication the ward takes, and in general, take charge of the ward’s daily activities. Conservators, on the other hand, take charge of a person’s finances, property, businesses and other financial affairs.

Guardianships and conservatorships are very serious matters. They may extinguish certain basic individual rights of the allegedly incapacitated person who is the subject of the court action and, once a guardian or conservator is appointed, the individual's consent is not required to make decisions. The court needs to be assured that the individual's rights are observed and an appropriate person is appointed as guardian or conservator. This can result in a long and expensive court process. After appointment, the court exercises oversight of the guardianship or conservatorship by requiring annual reports from the guardian and conservator regarding living arrangements, condition of the ward, the ward's financial situation and other information.

When the Uniform Guardianship and Protective Proceedings Act (UGPPA) went into effect in Hawai'i in 2005, the terminology used in the law in Hawai'i changed from "guardian of the person" and "guardian of the property" to "guardian" and "conservator," respectively. Other terms are "ward," which refers to the person for whom guardianship is sought and "protected person," which refers to the person for whom a conservatorship is sought. Different terms may be used in different states.

As previously mentioned, guardianship and conservatorship involve the legal processes through which someone is appointed by the court to take care of the person or property of an individual who is determined to be incapable of handling personal and property matters. Hawai'i courts have jurisdiction over guardianships for people domiciled or present in the state and over conservatorships for people who are domiciled and own property in Hawai'i. Court hearings for guardianships of incapacitated persons can be heard in Circuit (Probate) Court or in Family Court. This is what is called "concurrent jurisdiction." Hearings for conservatorships are in the Circuit (Probate) Court. Cases involving the guardianship and conservatorship of the same person can be consolidated in the Circuit (Probate) Court at the court's discretion. Petitioners are the individuals who ask the court for the responsibility of caring for and protecting another person. Petitioners can act both as the guardian and as the conservator of an incapacitated person. Finally, transfer of jurisdiction from one court to another is permissible, if it is determined to be in the best interest of the ward or protected person.

Under the UGPPA, a guardianship or a conservatorship for a person or property, is appropriate if that person, 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.”

As noted above, the appointment of a guardian or a conservator usually requires rather lengthy and often expensive procedures. The petitioner (i.e., the person who appears before the court to request the appointment of a guardian or conservator), will need to provide medical and personal information about the incapacitated person, the spouse, parents, children, other close relatives, current custodian or guardian, and the proposed guardian or conservator. The court will require confirmation of the incapacitated person’s condition, usually through a written report from a doctor. The court must also find that it has jurisdiction over the incapacitated person, and property if a conservatorship is required, that the appointment is in the person’s best interest, and that it is necessary or desirable to continue the care and supervision of the incapacitated person.

A guardianship or conservatorship will last until the death, resignation, removal, or court termination of the guardian or conservator. The ward (under a guardianship) or the protected person (under a conservatorship) can also petition the court to terminate the guardianship or conservatorship when the person regains or attains the capacity or ability to take care of personal and property matters.

GUARDIANSHIP

Generally, a guardian can be appointed by a judge based on a petition that meets certain statutory requirements and which complies with other measures required by the court, such as proper notice to the interested parties. Except as otherwise limited by the court, a guardian has the duty to make decisions regarding the ward’s support, care, education, health, and welfare. The guardian should only exercise authority as necessitated by the ward’s limitations and, to the extent possible, should encourage the ward to participate in making decisions for himself or herself. The guardian should also encourage the ward to regain or attain the capacity to manage the ward’s own affairs.

Among other powers, the guardian will generally have the authority to take custody of the ward and establish the custodial dwelling within this state (or outside the state with the court's authorization). The guardian will also be authorized to consent to medical or other care, treatment or service for the ward, to take action to compel support for the ward, and to apply for and receive moneys for the support of the ward. Making decisions to accept or to refuse life-sustaining medical treatment, especially at the end of life is one of the customary decisions a guardian may make for an incapacitated ward in accordance with the court's guardianship order.

Please note: a guardian, without authorization of the court, may not revoke any health care directions or any individual instructions set forth in any medical directive or health care power of attorney of which the ward is the principal. However, the appointment of a guardian automatically terminates the authority of any agent designated in the medical directive or health care power of attorney.

Public Guardian

As a state-funded program at the State of Hawai'i Judiciary, the Office of the Public Guardian (OPG) serves as guardian for mentally incapacitated adults if there is no willing and suitable person, family member, relative, or close friend who can serve.

The OPG also provides temporary guardianship in emergency situations. While the OPG can be appointed guardian of the ward, it does not file the petition with the court to be appointed. Other organizations, including health care institutions, legal services agencies, private practice attorneys, or private individuals must file the petition with the court and obtain the appropriate documents to name the OPG as guardian.

Private individuals can represent themselves in court and file a petition on behalf of the incapacitated person with the assistance of a "*pro se* packet." Information about such "do-it-yourself" packets is available through the OPG and the Family Court. However, the court system can be confusing and it is often a good idea to get a lawyer to help.

CONSERVATORSHIP

A conservatorship may be determined to be necessary under a variety of circumstances for the protection of the property (sometimes called estate) of an incapacitated individual. The court may determine that the individual is unable to manage property and business affairs because the individual cannot comprehend and evaluate information or make or communicate decisions even with help or because the individual is missing, detained, or unable to return to the United States. The court may also decide that unless management is provided, the property will be wasted or dissipated. Further, the court may decide that a conservatorship is necessary or desirable when money is needed for the support, care, education, health, and welfare of the individual or of individuals who are entitled to this support.

Generally, without needing further court approval, a conservator may authorize, direct, or ratify any transaction necessary or desirable to provide for the security, service, or care of the ward or protected person. The appointment of a conservator vests title in the conservator as trustee to all property of the protected person or to the part of the property specified in the court order. Upon notice of the appointment of a conservator, all agents acting under a previously created power of attorney by the protected person, must take no further actions without the direct written authorization of the conservator, and must promptly report and account to the conservator any and all actions taken under the power of attorney. Each year the guardian and the conservator must prepare an accounting and submit it to the respective court.

Conservatorships for Estates Less Than \$10,000

When the value of all of the protected person's assets (the estate) is less than \$10,000, the Clerk of the Circuit Court may be appointed to act as conservator and will be responsible for properly receiving and dispensing the protected person's funds. In addition to managing and administering funds for protected persons, the Estate and Guardianship clerks communicate with caregivers, guardians of the person, public agencies, and provide many other services that ensure that the protected person's funds are properly administered.

Although it is possible to have the Clerk of the Circuit Court establish a conservatorship for a protected person with assets of less than \$10,000 at the

Small Estates and Guardianship Office, be aware that its resources may be limited and its workload very high.

To start the process, contact the Small Estates and Guardianship Office. Among other documents, it will ask for a letter from a physician stating that the incapacitated individual is incapable of managing financial affairs and in need of a conservatorship. To help determine if the incapacitated individual is qualified to have the Clerk of the Circuit Court become the conservator, the Small Estates and Guardianship Office will require names and addresses of family members and other information, such as bank accounts, to determine the value of the assets.

After the necessary information and documents have been submitted and approved, the Small Estates and Guardianship Office will prepare a petition for conservatorship. If the judge approves the petition, the protected person's bills and checks can be sent directly to the Small Estates and Guardianship Office for payment. The conservatorship will continue until the protected person dies, once again becomes capable of handling financial affairs, or until a successor conservator is appointed.

Once the estate reaches a certain sum in value (currently \$16,250), a conservator must be appointed or the court, in its discretion, may allow the conservator appointed under this section to continue to act even though the total assets exceed that amount.

Trust Companies and Attorneys as Conservators

Being a conservator can be complicated, time consuming, and require a great deal of responsibility. For these reasons, friends and family members are not the only ones who can be appointed as a conservator. However, be mindful that an owner, operator, or employee of a long-term care institution at which the respondent is receiving care shall not be appointed as conservator unless related to the respondent by blood, marriage, adoption, or otherwise ordered by the court. Where substantial assets are concerned (usually in excess of \$100,000), private trust companies and private attorneys are usually willing to be conservators for protected persons. To establish a conservatorship, these entities, caregivers, or financial organizations must go through the same proceedings as do private individuals.

Kōkua Kānāwai, Guardian Ad Litem, and Counsel

In Hawai'i, the judge will sometimes appoint an independent investigator to serve as an extension of the court to conduct an independent review in a guardianship or conservatorship proceeding. The *kōkua kānāwai* (which means "Helper in the Law") is usually an attorney whose duties include interviewing the parties to the case, reviewing financial and medical records and submitting a written report of findings and recommendations to the judge. The *kōkua kānāwai* does not advocate for or against the rights of the incapacitated individual. The *kōkua kānāwai* charges the conservatorship estate for services.

Additionally, when necessary, and completely independent of the *kōkua kānāwai* recommendations, the court has the authority to appoint a guardian *ad litem* for a person who is the subject of a guardianship or conservatorship proceeding during the course of a case. While typical guardians or conservators have an on-going duty to protect the interests of their ward, guardians *ad litem* only protect their ward's interests in a single case.

The court may also appoint counsel for the subject of the proceeding if the court finds that the individual is a vulnerable adult, requires a separate legal advocate and is unable to afford private counsel.

ALTERNATIVES TO GUARDIANSHIP AND CONSERVATORSHIP

A guardianship or a conservatorship can involve significant time delays, costs, and a potential loss of privacy. Obtaining the required documents (such as birth certificates, marriage certificates, and a 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 incurred with each proceeding. Further, while guardianship proceedings are usually confidential, conservatorship documents and proceedings are matters of public record and, accordingly, the financial affairs of the ward or protected person may become public knowledge.

With proper advance planning, guardianship or conservatorship proceedings may not be necessary. Less restrictive alternatives can serve the purpose of

providing necessary assistance to an incapacitated adult. Advance directives for health care (to be discussed in the next chapter), financial and legal powers of attorney, living trusts, representative payeeships, and joint financial accounts to pay bills are a few of the frequently used alternatives.

POWERS OF ATTORNEY AND THE UNIFORM POWER OF ATTORNEY ACT

A power of attorney (POA) can be an important alternative to both guardianship and conservatorship. A power of attorney is a written instrument through which a person (called the “principal”) designates another person as an agent (or “attorney-in-fact”) and grants the agent authority to perform certain acts on the principal’s behalf. It is a dynamic tool that can be used in planning for incapacity by authorizing someone to act on behalf of another person in private affairs, business, or some other legal matter. Although it has all these attributes that enable the agent to do a lot of things, the agent cannot make health care decisions.

Powers of attorney can be drafted to take effect immediately or on a future date. A “springing” power of attorney “springs” into effect upon some subsequent future event such as a particular date or upon the principal’s disability or incapacity. A power of attorney can also be made for a specific period or can last indefinitely, until the principal’s death. Upon the principal’s death, the personal representative or trustee named in the principal’s will or trust, if applicable, will take charge.

Caution:

You do not give up any of your powers to make decisions for yourself if your power of attorney is drafted to take effect immediately as long as you remain mentally capacitated. You also retain the right to revoke or to change your power of attorney at any time as long as you remain mentally capacitated. You should know that some government agencies do not accept powers of attorney or may require or recommend specific forms. The Internal Revenue Service has its own Power of Attorney Form 2848, which the IRS requires in designating an agent. The Social Security Administration does not recognize powers of attorney but has its own forms and processes to appoint a

representative payee for individuals who need help with managing their Social Security benefits. You can obtain more information and applications for this process at <https://www.SSA.gov>

THE UNIFORM POWER OF ATTORNEY ACT (UPOAA)

The 2014 Uniform Power of Attorney Act (UPOAA) was passed into law to make it easier for a properly executed power of attorney to be accepted by banks, financial institutions and ordinary citizens. Part of the reason for the change was that powers of attorney, historically, were not required to be accepted. Financial institutions, especially, were not required to accept them. Under the new law, when the power of attorney is presented to a third party, such as a bank, that party now has three choices – to accept it, to request that the agent sign a certificate, or to request the agent to provide an opinion of counsel.

The law applies to all powers of attorney in Hawai'i, with a few narrow exceptions, such as health care directives, voting proxies, parent/guardian agreements for care of ward/children by third parties, and powers granted via governmental forms. It applies retroactively to all powers of attorney, whether executed before or after passage of the Act. Powers of attorney executed outside of Hawai'i remain valid if they were executed in compliance with the law of that jurisdiction.

Hawai'i's law provides a statutory form which may be used or modified. The statutory form provides a listing of general powers to be granted by initialing each subject the principal wants to include in the agent's general authority and, if the principal wishes to grant general authority over all of the subjects, the principal may initial "All Preceding Subjects."

The subjects are explained in the statute but not on the statutory form and are listed as: "Real Property, Tangible Personal Property, Stocks and Bonds, Commodities and Options, Banks and Other Financial Institutions, Operation of Entity or Business, Insurance and Annuities, Estates, Trusts, and Other Beneficial Interests, Claims and Litigation, Personal and Family Maintenance, Benefits from Governmental Programs or Civil or Military Service, Retirement Plans and Taxes."

The extent of powers is not always obvious. While these provisions are intended both to alert the principal to the extent of the authority being delegated and as information to third parties about the agent's authority to conduct those transactions, practically speaking, it is not difficult to convince someone to "just initial here if you trust me."

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 a lawyer 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 submitted to a court, at least there could be some mechanism to assure that the powers were utilized in a fiduciary capacity. In the same vein, as long as the principal is still mentally capacitated, the principal can revoke or modify the power of attorney at any time.

For a practical approach towards greater protection, individuals executing powers of attorney could be encouraged to utilize the optional "Special Instructions" section of the statutory form. This provides a good area to include or reference a "What Matters to Me" type of statement for future use in times when family, fiduciaries and courts may wonder, "What would they have wanted?" Lawyers will need to establish guidelines and language that would be both helpful and legally sufficient. Lawyers can also encourage the use of the agent's certification, which is an optional form that may be used by an agent to certify facts concerning a power of attorney. This certification includes information about the agent's duties and liability. While this does not by any means ensure that the agent will not misuse the power of attorney, it may give the agent pause.

The UPOAA became effective upon signing in April 2014 and was codified in the Hawai'i Revised Statutes. The UPOAA repealed the previous Uniform Durable Power of Attorney Act. If you have a power of attorney (other than a health care power of attorney) executed prior to the April 2014 effective date of the statute, consult with your attorney to see if you should make a new one under the UPOAA.

The UPOAA provides a comprehensive legal framework for the creation and use of POAs and furnishes specific guidance to and protections for principals, agents and third parties. "Principal" means an individual who grants authority

to an agent in a power of attorney. “Agent” means a person granted authority to act for a principal under a power of attorney, whether called an agent, attorney-in-fact, or otherwise. The term includes an original agent, co-agent, successor agent, and a person to which an agent’s authority is delegated. “Person” means an individual, corporation, business trust, estate, trust, partnership, limited liability company, association, joint venture, public corporation, government or governmental subdivision, agency, or instrumentality, or any other legal or commercial entity.

A power of attorney must be signed by the principal or in the principal’s “conscious presence” by another individual directed by the principal to sign the principal’s name on the power of attorney. A signature on a power of attorney is presumed to be genuine if the principal acknowledges the signature before a notary public or other individual authorized by law to take acknowledgments.

The UPOAA contains several mandatory provisions and a number of “default” provisions. A default provision is a provision that applies unless overridden by express language in the POA and is usually preceded by the phrase “unless the power of attorney otherwise provides.” The UPOAA’s default provisions present a variety of drafting options that allow it to be individually tailored to a principal’s needs, interests and preferences. Under the UPOAA, a POA by default is a “durable” power of attorney. “Durable” means not terminated by the principal’s incapacity, with respect to a POA. This means that the POA survives the incapacity of the principal and helps avoid the need to initiate expensive and time-consuming conservatorship actions to care for the principal’s assets.

The UPOAA serves to enhance the effectiveness of the POA as a vehicle that an individual can use to plan for potential incapacity and to avoid a court appointed conservatorship in the event of actual incapacity. “Incapacitated” or “incapacity” means the inability of an individual to manage property or business affairs because the individual:

- Has an impairment in the ability to receive and evaluate information or make or communicate decisions even with the use of technological assistance; or
- Is missing, detained, (including incarcerated in a penal system), or is outside the United States and is unable to return.

The UPOAA also serves to prevent, identify and redress the misuse or abuse of a POA by an agent. The law is aimed at striking a balance between preserving the durable power of attorney as a flexible, low cost, and private form of surrogate decision-making and deterring its use as a tool to financially abuse incapacitated individuals.

The law incorporates language used in different jurisdictions pertaining to guardians and conservators. For example, in some states, conservatorship may be called guardianship of the property and in some states, conservatorship includes both matters involving the person and the person's property. Nevertheless, if protective proceedings for the principal's estate or person are begun after the principal executes the POA, the court might consider appointing the conservator or guardian (or whatever term the jurisdiction uses) that the principal had previously nominated in the POA. Usually, except for good cause shown or disqualification, the court makes its appointment in accordance with the principal's most recent nomination in the POA or another legal document.

Under the UPOAA certain specific powers rather than general powers are conferred. This helps eliminate questions about the agent's authority while ensuring that the agent is aware of the fiduciary responsibilities as agent. The UPOAA requires the agent to act in good faith and within the scope of authority granted in the power of attorney.

"Good faith" means honesty in fact. The UPOAA provides a form that generally must be accepted by any third parties. There are civil penalties for refusal to accept it if the third party has the principal's assets. Basically, if a person is leery about accepting the POA, the person can request an agent's certification under penalty of perjury of any factual matter concerning the principal, agent, or power of attorney. The third party can also request an English translation of the power of attorney if the power of attorney contains, in whole or in part, language other than English. Lastly, the third party can make a written request stating the reason for a written opinion of counsel as to any matter of law concerning the power of attorney.

With a few exceptions, a person must either accept an acknowledged power of attorney or request a certification, a translation, or an opinion of counsel no later than seven business days after presentation of the power of attorney

for acceptance. If a person requests a certification, a translation or an opinion of counsel, the person must accept the power of attorney no later than five business days after receipt of the certification, translation or opinion of counsel. A person may not require an additional or different form of power of attorney for authority granted in the power of attorney presented.

Protections and Penalties

A legal and financial power of attorney is a very powerful tool. It allows you to appoint another to handle legal and financial matters on your behalf if you are incapacitated, or, in some cases, if you are unable or unavailable or simply want someone to help you. Granting power to another person can also make you vulnerable to fraud, abuse or exploitation. Your agent may exercise legal authority or gain access to your funds without your specific permission or knowledge. What can you do to lessen the risk?

First, you must attempt to verify and then hope and trust that your agent is honest and will act on your behalf and for your benefit. Children and grandchildren often are appointed as agents but can easily succumb to temptation when power or money is accessible. If contracts are signed on your behalf, you may be liable for the obligations and when the money is spent, without your specific knowledge or consent, it may be difficult to retrieve it.

The use of limited powers of attorney or “springing” powers of attorney upon incapacity may not be as flexible as one that is immediately effective, but it is a consideration. Consult with your attorney to talk about these options and perhaps to set up accountability mechanisms in your power of attorney, including a “What Matters to Me” type of statement in the special provisions section of the power of attorney or in a separate form.

There are specific provisions under the UPOAA that can help protect the principal from a dishonest agent. An agent who violates this chapter shall be liable to the principal or the principal’s successors-in-interest for the amount required to restore the value of the principal’s property to what it would have been had the violation not occurred; and to reimburse the principal or the principal’s successors-in-interest for the attorney’s fees and costs paid on the agent’s behalf.

Under the UPOAA, a POA terminates when the purpose for the power of attorney is accomplished; or when the principal revokes the agent's authority; or the agent dies, becomes incapacitated, or resigns, and the power of attorney does not provide for another agent to act under the power of attorney.

The statutory form used in Hawai'i is easily accessible. A sample form, among other forms, can be found at hawaii.edu/uhelp/online-forms.htm Use extreme caution in using this form. Be sure to first seeking advice and counsel from your attorney. Remember that you can revoke or change your power of attorney as long as you are mentally capacitated. Also remember to ask your attorney about making a "What Matters to Me" type of statement in the special instructions section of the power of attorney or in a separate form.

Revoking a Power of Attorney

To revoke a power of attorney, the principal can create a document called a "Revocation of Power of Attorney" or create a new power of attorney that indicates the previous power of attorney is revoked. A principal can rescind a power of attorney at any time, even if the power of attorney has a specified end date, so long as the principal is competent and the agent is notified.

The principal can also prepare, sign, and give a document called "Notice of Revocation" to the agent and other individuals, institutions or agencies who might have dealt with the original power of attorney document. Make sure that they receive a copy of the revocation. Third parties (such as banks or the Bureau of Conveyances if you registered your power of attorney) should also be notified of the revocation.

In addition, if the power of attorney document was registered (which means it was filed with a certain agency such as the Bureau of Conveyances), the revocation must also be registered.

MONEY MANAGEMENT

One of the most common reasons that an older adult becomes the subject of conservatorship proceedings is that the individual has difficulty handling 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 arranging for financial counseling.

While many people still pay bills and manage their investments through checks and other paper transactions, computers, smart phones and other Internet devices 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, credit and debit card purchases, and⁵⁴ many other functions.

Close family members can provide basic, simple money management services electronically over the Internet. For example, a daughter living on one island can easily make bill payments (including utility and credit card payments) for her parents on another island, just the way she makes her own bill payments. She can also manage savings accounts, mutual funds, stock portfolios, and other financial assets, and can even file federal and state tax returns over the Internet.

A word of caution—there are many schemes and scams perpetrated, especially since Internet and telephone transactions do not occur face-to-face. Be very cautious to whom you reveal your bank account information or to whom you entrust your ATM bank card, especially to people or companies you do not know. Always check your bank and credit card statements and report any unauthorized use immediately.

In addition to electronic banking systems that can be used by informal caregivers, there are non-profit and for-profit agencies that do money management, usually for a fee. If you use these services, make sure that the money manager is insured and bonded to protect you from theft or loss.

Social Security Checks

Social Security or Supplemental Security Income benefits should be paid electronically if possible. If you are still receiving checks, the US Department of the Treasury will contact you about complying with the requirement. It can

grant exceptions in rare circumstances. For more information, visit ssa.gov or call Social Security's toll free number: 1-(800) 772-1213. To request a waiver, visit <https://www.ssa.gov/deposit/EFT%20Waiver%20Form.pdf> or call the Department of the Treasury at 1-(855) 290-1545.

Direct deposit is a program that electronically delivers incoming checks directly to a personal checking or savings account at a designated bank or other financial institution. The Social Security Administration strongly encourages all Social Security and SSI (Supplemental Security Income) beneficiaries to receive their monthly benefits by direct deposit because it is faster and safer than receiving a check through the mail. When signing up for direct deposit services, it would be helpful to have a personal check, bank statement and your Social Security number handy. Most banks, savings and loans and credit unions offer a variety of accounts, some requiring low or no fees. More information about how direct deposit works can be obtained at your bank, savings and loan or credit union, or at Social Security. Signing up for direct deposit can also be done online through the Internet. For Social Security and SSI recipients without bank accounts, contact Social Security to find out what your options are.

Once you set up a direct deposit account, you may also wish to set up an automatic payment system to pay for recurring bills such as electricity, water, mortgage and insurance payments. It takes the worry out of remembering to make payments.

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 person who is helping, access to the funds. Caution: 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, anytime.

Representative Payees and Fiduciaries

When a person has memory loss, is incapacitated, or does not understand the process of paying bills or money management, a representative payee or fiduciary can be appointed to handle government benefits. For Social Security benefits, upon appointment, the representative payee receives checks (or

direct deposit of funds) from the Social Security Administration and must use the money for the needs of the beneficiary.

Once a representative payee (often a caregiver or family member) is appointed, the representative payee will need to decide how best to use the funds for the beneficiary's personal care and well-being. The Social Security Administration requires that any money left after meeting the beneficiary's current and reasonably foreseeable needs must be saved and maintained for the beneficiary. Periodically, the Social Security Administration will ask the representative payee to complete a form to account for funds received. A representative payee is also required to keep Social Security informed of changes that may affect the beneficiary's eligibility for benefits.

Although some groups of payees no longer have to complete the annual Representative Payee Report, all payees are responsible for keeping records of how the payments are spent or saved and making all records available for review if requested by SSA. See: <https://www.ssa.gov/payee/>

Similarly, the Department of Veterans Affairs (VA) Fiduciary Program was established to protect veterans and other beneficiaries who, due to injury, disease, or incapacity, are unable to manage their financial affairs. The VA will determine an individual to be unable to manage financial affairs after receipt of medical documentation or adjudicated by the court. Upon determining that a beneficiary is unable to manage financial affairs, the VA will appoint a fiduciary. The fiduciary, normally chosen by the beneficiary, and often being a family member, must undergo an investigation of suitability to serve.

Be aware that the Treasury Department does not recognize a power of attorney for negotiating federal payments, including Social Security or SSI checks. This means, that if you have a power of attorney for someone who is incapable of managing benefits, you must still apply to serve as representative payee.

Pension Funds Verification Form

Many pension funds require that retirees complete a pension payment eligibility verification form each year verifying that they are alive and are receiving the benefits to which they are entitled. Similarly, many organizations and agencies are required to verify pension and annuities income for programs that they

operate and to examine this income periodically. Some housing authorities also ask for periodic verification of information. These types of verifications and requests for release of information are not usually a problem for those individuals who are still mentally capacitated, but difficulties may arise if the person receiving the pension or annuity or benefit is not capable of responding to the request for information. Some funds, agencies and organizations may accept verifications made by family members or authorized representatives such as agents in powers of attorney, but others may require verification by guardians or conservators or may have other requirements. Needless to say, a person would be wise to try to find out ahead of time what the requirements may be.

TRUSTS

A trust can be used as an effective estate planning tool and to some extent, as an alternative to conservatorship, a court process that appoints someone to manage an incapacitated person's financial affairs. A trust is an arrangement that you, the maker of the trust (also called the settlor or the grantor) set up to transfer your property to a trustee (who could be yourself or someone else or an institution like a trust company) to hold for you and/or your beneficiaries.

You can decide the terms of the trust in a trust agreement. The trust can be used to manage any property you place into it. This can include your home, rental properties, vehicles, bank and savings accounts, stocks, bonds, and virtually anything you can hold title to. The trustee can use and manage assets in accordance with the instructions in the trust and can be held fiduciarily responsible for their actions. A successor trustee can be named to administer the assets in the trust if the trustee, who could be you, is unable to do so. By having these arrangements set out in the trust, there can be someone to take charge of administering the trust assets when the trustee is unavailable. Thus, establishing a conservatorship for the trust assets, which may be time-consuming, can be avoided.

There are several different types of trusts, each of which is created for a different purpose. For example, you can create a "testamentary trust" in your will, which does not take effect until you die. Note, however, that in a testamentary trust, property must go through the probate process before it passes into the trust.

It is not an alternative to conservatorship and does not avoid probate. There are also “special needs trusts” which we will cover under the discussion of Medicaid. Special Needs Trusts are trusts created to allow a person with a physical or intellectual disability or a chronically ill person to receive income without being disqualified from receiving public benefits.

Trusts can also be revocable or irrevocable. In a “revocable living trust” you can give your trustee instructions on how to manage the property during your lifetime and upon your death. You can give instructions on how much income and principal you want to distribute, who gets the property when you or other beneficiaries die, what the trustee’s fee is for the work, and so on. There is no requirement to involve a trust company. Revocable trusts allow the maker of the trust to amend or revoke the trust at any time. Irrevocable trusts cannot be amended or revoked. Once you transfer assets into an irrevocable trust, you relinquish control of them.

Remember, in addition to your living trust, you should have a will to take care of all other assets that may not have been placed or transferred into the trust. If you create a living trust, make sure that you or your attorney places or transfers your property into the trust. If you fail to change the title of your property to that of your trust, the trust cannot control that property. You should be aware that revocable living trusts usually cannot be used to get around eligibility guidelines for such assistance programs as Medicaid. There may be certain times when you do not want to place real estate in a trust if you are concerned about qualifying for Medicaid.

Before deciding whether to utilize a trust for your estate planning purposes you should talk with an attorney who is skilled in this area of law and you should probably avoid “living trust kits” if you do not know what you are doing in this increasingly complex area. And do not forget to transfer the title of your property (real estate, intellectual property, bank accounts, vehicles, boats, etc.) to the trust. Under this framework you can be a little more assured that your assets will be used for your care and for the payment of your bills in the event you are not able to do so. A court-appointed conservator could accomplish the same thing, but court actions take time and money, and many matters could remain unfinished while the conservatorship is being pursued.

CHAPTER 3

PLANNING FOR MEDICAL TREATMENT, HEALTH CARE DECISIONS, AND DECISIONS AT THE END OF LIFE



MEDICAL TREATMENT AND INFORMED CONSENT

During the Covid-19 pandemic, there was a new sense of urgency and interest in advance health care planning to help ensure that patients' wishes were accurately documented and respected. Right from the beginning of the crisis, and through different virus variants, there was a demand for information and an increase in completing advance directives. With the pandemic experience in mind and as both science and medical treatment protocols progress and allow people to live healthier and longer lives, more individuals are deciding to take charge of their own medical decisions. Some may wish to consult with physicians, family members, clergy, and friends. Others may prefer privacy.

In Hawai'i, as in all other states, competent individuals have the fundamental right to control decisions relating to their own medical care. This includes decisions whether to have life-sustaining medical treatment or surgical procedures provided, continued, withheld, or withdrawn. The basis for making medical treatment decisions lies in the concept of informed consent. In Hawai'i, the Hawai'i Medical Board establishes standards for health care providers to follow in giving information to a patient or to a patient's guardian, health care

agent or legal surrogate, if the patient lacks the capacity to give an informed consent. The standards include provisions which are designed to reasonably inform a patient, a patient's guardian or legal surrogate of the following:

- The condition to be treated;
- A description of the proposed treatment or surgical procedure;
- The intended and anticipated results of the proposed treatment or procedure;
- The recognized possible alternative forms of treatment;
- The recognized alternative treatments or procedures, including the option of not providing these treatments or procedures;
- The recognized material risk of serious complications or mortality associated with:
 - the proposed treatment;
 - the recognized alternative treatments or procedures; and
 - not undergoing any treatment or procedure; and
 - the recognized benefits of the recognized alternative treatments or procedures.

Health Care Decisions

Laws such as the federal Patient Self-Determination Act encourage individuals to decide how health care decisions will be made when they are no longer able to make these decisions for themselves. No matter what an individual desires, it is important to communicate those desires so that health care providers will know what to do when that person can no longer make decisions. In determining how an individual wants to be treated, an individual may want to discuss these matters with family, friends, clergy and other advisors. Individuals should make sure that these personal desires are made known to concerned individuals and especially to health care providers.

Health care encompasses much more than medical treatment and decisions about end-of-life issues. In Hawai'i, the Uniform Health Care Decisions Act (Modified) defines health care as any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect an individual's physical or mental condition, including:

- Selection and discharge of health care providers and institutions;

- Approval or disapproval of diagnostic tests, surgical procedures, programs of medication and orders not to resuscitate; and,
- Directions to provide, withhold, or withdraw artificial nutrition and hydration, provided that withholding or withdrawing artificial nutrition or hydration is in accord with generally accepted health care standards applicable to health care providers or institutions.

Crisis Standards of Care Triage Allocation Framework

Generally, mentally capacitated adults or their legally authorized representatives have the right to make health care decisions, including decisions to accept or to refuse medical treatment, including life-saving interventions. However, on September 1, 2021, the governor of Hawai'i signed an emergency executive order, which, among other matters, releases health care facilities and health care workers from liability if they have to ration care under a state-wide Crisis Standards of Care Triage Allocation Framework. One provision would enable hospitals to use age as a "tie-breaker" under certain circumstances to deny care to a person over 65 if medical intervention were needed for a younger patient.

The Crisis Standards of Care Triage Allocation Framework, if implemented, would have an effect upon our existing laws discussed in this chapter regarding informed consent, advanced health care directives, surrogate decision-making, do-not resuscitate (DNR) codes, and Provider Orders for Life-Sustaining Treatment (POLST). There has been some outcry regarding the use of age as a "tie-breaker" in Hawai'i in this triage policy but, as of the date of writing this chapter, this provision remains. This shows how difficult it is to predict what will happen to individuals, including older individuals, in the future, even with prior planning.

Health Information and HIPAA

With a few exceptions, patient records belong to the patient and such information is considered confidential. A federal law, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), 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. Due to the complexity and confusion of the HIPAA statute, people who need access to medical records on behalf of an incapacitated patient may have a difficult time gaining access to those records. They are required to produce evidence of their authority to receive medical information, including reviewing the medical record or chart, on behalf of the patient.

State or other law determines who is authorized to act as a personal representative for purposes of HIPAA. In Hawai'i, 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 appointed as a "designated surrogate" by the patient; or
- Has been selected as a "non-designated surrogate" by consensus of "interested persons."

For deceased patients, the personal representative or executor of the patient's estate may qualify.

ADVANCE HEALTH CARE DIRECTIVES

The term "Advance Health Care Directive," sometimes shortened to "Advance Directive," applies to all directives, instructions, or even desires that a person may communicate in writing, orally or in some other fashion, concerning decisions about medical treatment and health issues relating to one's body and life. The term "living will" was popular for many years but was confusing to many. In 1999, the Uniform Health Care Decisions Act (Modified), or UHCDA, was enacted in Hawai'i. This law uses the term "individual instruction" rather than "living will" which is still in use in several other states and by certain agencies, including the Department of Veterans Affairs.

Although advance directives are generally used in the context of making end-of-life decisions, the laws of Hawai'i 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 separate 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. As indicated in the previous chapter, powers of attorney for health care are no longer included under the provisions of the Uniform Power of Attorney Act but need to be completed in accordance with the UHCDA.

Although written advance directives concerning life-sustaining medical treatment are encouraged and preferred under Hawai'i law, they are not required to be written. They can be orally communicated. An adult or emancipated minor may give an individual instruction regarding their health care. The instruction, oral or written, may take effect immediately or be limited to take effect only if a specified condition arises.

In Hawai'i, advance health care directive formats generally follow the optional form found in Hawai'i'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 plan 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.

Individual Instructions for Health Care

A good way to make your desires known concerning health care decisions, including life-sustaining medical treatment is to make an "individual instruction"

in accordance with Hawai'i's current UHCDA. As previously mentioned, the individual instruction takes the place of what was commonly called the "living will" under the old law. Individual instructions may be made orally or in writing and can cover virtually all aspects of health care. If made orally, it may be best for you to provide the instruction directly to your doctor or other health care provider and ask them to document your discussions by placing the information you provide in your medical record or chart. You can provide an individual instruction in writing, for example, by writing a letter to your doctor. The letter can let your doctor know about your desires for health care in the future.

Usually, an individual instruction is incorporated into an advance directive document, which can also include the designation of an agent through a health care power of attorney, directions concerning organ donations, and the designation of a health care provider, among other matters.

The UHCDA provides an optional sample form with an accompanying explanation. Sample long and short forms can be found at hawaii.edu/uhelp/online-forms.htm

In the long form, choices are provided for you to express your wishes regarding the provision, withholding, or withdrawal of treatment to keep you alive, including the provision of artificial nutrition and hydration, as well as the provision of pain relief medication. Space is provided for you to add to the choices you have made or for you to write in any additional wishes. This form may be modified to suit your needs, or you may use a completely different form.

During the Covid-19 pandemic, many individuals sought to clarify their advance directives, often with a focus on supplemental oxygen. Several organizations developed Covid-19 supplements, an example of which may be found on the UHELP website hawaii.edu/uhelp

Health Care Power of Attorney

In addition to the "individual instruction" for health care, you should consider making a health care power of attorney. This is also called a "durable power of attorney for health care" or "medical power of attorney" and can be done in the advance health care directive under the UHCDA. Once again, do not confuse

the durable power of attorney for health care, which expressly addresses health care decisions and has different execution requirements, with the powers of attorney under the Uniform Power of Attorney Act discussed in Chapter 2.

If you are confused about the type of power of attorney you have, make sure to ask an attorney for advice and guidance. Giving a trusted health care agent the authority to carry out your individual instructions or to make health care decisions in the absence of such instructions is becoming a common method of planning for the future. It lets you continue to stay in charge of your own destiny. To help enhance your future autonomy and self-determination, consider filling out a “What Matters to Me” type of statement in your advance directive. There is space for these statements in the sample forms found at hawaii.edu/uhelp/online-forms.htm

Under Hawai'i 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. 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 if your primary agent will be available to make decisions when needed.

Unless related to you, your agent may not be an owner, operator, or employee of a health care institution where you are receiving care. 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.

Execution and Witnessing

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. In the alternative, 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 employee of a health care provider or facility, or the agent you have designated in your health care power of 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 you, the principal, by blood, marriage, or adoption, nor entitled to any portion of the estate upon your death under any will or codicil you may have made prior to the execution of the power of attorney for health care or by operation of law then existing.

What to Do with Your Advance Health Care Directive

When you complete an advance directive, which can include individual instructions and/or a power of attorney for health care, give a copy of any signed and completed form to your physician, to any other health care providers you may have, to any health care institution at which you are receiving care and to any health care agents you have named. You should talk to the person you have named as agent to make sure that your agent understands your wishes and is willing to take on the responsibility. Once again, make sure that you consider designating alternate health care agents in case your first choice is unwilling or unable to act on your behalf.

Make certain that a copy of your executed document is placed into your medical record or chart. This is usually done electronically. You may have several medical records or charts if you receive health care from several providers. This is your responsibility. In case of an emergency that requires a decision concerning your health care, make sure that you keep a copy where it is immediately available to your agent.

You can ask to have the initials, AHCD (Advance Health Care Directive), put on your driver's license or state identification card to indicate that you have made an advance directive. This will encourage people to look for the advance directive in an emergency, if for some reason you have not had it placed in your medical record or chart.

Revocation/Effectiveness of Advance Health Care Directives

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. Except for the donation of your body or body parts under Hawai'i's Uniform Anatomical Gifts Act, a health care power of attorney ceases to be effective upon your death.

OTHER HEALTH CARE DOCUMENTS

Surrogate Decision-Making

During the Covid-19 pandemic, it was clear that many individuals who became sick and hospitalized had not completed advance directives. 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 but there is no default “family consent” law in Hawai'i. Since 1999, Hawai'i's UHCDA has provided a mechanism for “surrogates” to make decisions for incapacitated individuals. A surrogate may make a health care decision for a patient who is an adult or emancipated minor if the patient has been determined by the primary physician to lack capacity and no agent or guardian has been appointed or the appointed agent or guardian is not reasonably available.

Under the UHCDA surrogate provisions, a patient may designate or disqualify any individual to act as a surrogate by personally informing the supervising health care provider. 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.” In other words, a “designated surrogate” may make all decisions for the patient. In the absence of such a designation, or if the designee is not reasonably available, a so-called “non-designated surrogate” may be appointed to make a health care decision for the patient.

The process of appointing a “non-designated surrogate” is somewhat complicated under Hawai‘i’s modified version of the UHCDA:

- 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. Under this law, “interested persons” means the patient’s spouse, unless legally separated or estranged, a reciprocal beneficiary, a civil union partner, 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 who is familiar with the patient’s personal values.
- 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.
- 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.

The law 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 ambiguous and subject to interpretation. 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 regarding such health care issues.

The law provides that the “non-designated surrogate” shall make health care decisions for the patient based on the wishes of the patient, or, if those wishes are unknown or unclear, in the patient’s best interest.

The decision of a “non-designated surrogate” regarding whether life-sustaining procedures should be provided, withheld, or withdrawn shall not be based, in whole or in part, on either a patient’s preexisting, long-term mental or physical disability, or a patient’s economic status. A “non-designated surrogate” must inform the patient, to the extent possible, of the proposed procedure and the fact that someone else is authorized to make a decision regarding that procedure.

Due to the ambiguity of the authority the non-designated surrogate to make decisions concerning withholding or withdrawing tube feeding, an individual in Hawai‘i should consider making individual instructions for health care and designating an agent in a health care power of attorney or, at as an alternative, designating a surrogate by informing the supervising health care provider.

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. A sample declaration form can be found at hawaii.edu/uhelp/online-forms.htm

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. The Hawai‘i Department of Health’s program for out-of-hospital DNRs, often referred to as “Comfort Care Only” (CCO-DNR) or “Rapid Identification Documents,” has been suspended indefinitely although bracelets and necklaces issued under the program are still recognized. Wearing a state-approved CCO-DNR necklace or bracelet notified emergency medical services personnel, first responder personnel, and health care providers not to administer chest compressions, rescue breathing, defibrillation, or medication to restart the heart or the person’s breathing and that the person was to receive comfort care only (CCO), including oxygen, airway suctioning, splinting of fractures, pain medicine, and other measures required for comfort. Once again, this program has been suspended indefinitely and POLST forms, described below are intended to take its place.

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 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.

Provider Orders for Life-Sustaining Treatment (POLST)

In 2009, the Hawai’i legislature passed a law providing for a health care protocol called Physician Orders for Life-Sustaining Treatment (POLST). In 2014, the Hawai’i legislature passed legislation providing for the expansion of the existing law to give advanced practice registered nurse (APRN), in addition to physicians, the authority to sign what are now called Provider Orders for Life-Sustaining Treatment. 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. By law, the POLST form is not an advance directive but a provider’s order signed by a physician or an APRN and, accordingly, is immediately actionable.

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 provider’s order that is signed by either the physician or APRN and the individual or the guardian or health care agent or surrogate (legally authorized representative or LAR). The individual or the LAR is encouraged to discuss health care treatment decisions with the primary care doctor or APRN and document these decisions on a brightly colored POLST form, which as mentioned is then signed by both the individual or the LAR and the physician or APRN.

The form is lime green in color, so it can easily be found when needed and because it copies clearly on white paper. A plain white copy, completed correctly, and signed by the patient (or LAR) and by a doctor or an APRN is equally legal and valid. The form can be downloaded from the *Kokuu Mau* website www.kokuuau.org Briefly, a POLST provides the following:

- The orders contained in the standardized form are immediately actionable, signed medical orders;
- The orders address a range of life-sustaining interventions as well as the patient's preferred intensity of treatment for each intervention;
- The form is recognized by the Hawai'i Emergency Medical Services System;
- The form follows the patient between settings of care, including acute care hospitals, nursing facilities and community settings.

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.

FINANCING HEALTH CARE

As mentioned in the beginning of this handbook, to find out more about financing health care, visit <http://hawaii.edu/uhelp/handbook.htm> to look at the latest UHELP handbook and, specifically the chapter on health care financing, which will provide you with more details and which may help you avoid confusion between Medicare and Medicaid.

MEDICARE

Medicare is our country's health insurance program mainly for people age 65 or older. Certain people younger than age 65 can qualify for Medicare, too, including those with disabilities and those who have permanent kidney failure. Medicare is run by the Centers for Medicare and Medicaid Services, or

CMS (formerly Health Care Financing Administration), of the US Department of Health and Human Services (DHHS). Social Security Administration (SSA) offices across the country take applications for Medicare and provide general information about the program. Eligibility for Medicare is determined by the SSA. The CMS, a federal agency within the (DHHS), is responsible for the overall administration of the program. Medical bills and claims are handled by private insurance companies under contract with DHHS and monitored by the government. If you look at *medicare.gov* you will find that Medicare is not free and, in addition to eligibility requirements, can include premiums, deductibles, and co-insurance.

Medicare Coverage

There are three important rules to remember when Medicare coverage is an issue:

- First, Medicare covers care that is “reasonable and necessary” for the diagnosis or treatment of an illness or injury. Care is not considered reasonable and necessary, for example, if a doctor places a patient in a hospital or skilled nursing facility when the kind of care the patient needs could be provided elsewhere.
- Second, Medicare will not cover a stay in the hospital or skilled nursing facility longer than a patient needs to be there. Medicare coverage will end when further inpatient care is no longer reasonable and necessary.
- Third, Medicare coverage is limited. Medicare generally does not pay for long-term care. Medicare does not pay for help with activities of daily living or other care that most people can do themselves. Some examples of activities of daily living include eating, bathing, dressing, and using the bathroom. Medicare will help pay for skilled nursing or home health care when certain conditions are met, including a period of prior hospitalization.

Medicare Coverage for Alzheimer’s Disease

Several years ago, Medicare extended coverage to people with Alzheimer’s disease and other forms of dementia. In the past, patients were often automatically denied services when they were diagnosed with dementia on the theory that treatment was not considered “to improve functioning.” These

patients often did not receive such services as physical, occupational, mental health and speech therapy and home care. Under current policy, such services can be covered as long as they are determined to be reasonable and medically necessary. Unfortunately, Medicare still will not provide assistance for custodial in-home care or adult day care, long-term care in a nursing home or assisted-living costs. However, some services that are included under Medicare are the following:

- Home health care: Home care coverage under Medicare is available only if a patient is confined to the home and requires physical, occupational or speech therapy, or skilled nursing care, which will be provided from a home health agency under a doctor's plan of treatment. It is important to understand that Medicare likely will not pay for round-the-clock custodial care.
- Rehabilitation care including physical, occupational, or speech therapy: Patients must show that they can benefit from the therapy.
- Mental health services: Part B can cover physical, occupational and speech therapy, as well as psychological counseling if prescribed by a doctor. The counseling must be provided by a Medicare-certified therapist or mental health provider. Patients must show that they can benefit from the therapy.
- Hospice coverage: Medicare coverage is available for Part A beneficiaries, if a physician certifies that the patient is terminally ill (when life expectancy is six months or less), and if the beneficiary chooses to receive hospice care. The coverage is limited to the hospice care and frequently excludes the costs of room and board.
- Medicare pays for most outpatient prescription drugs which include drugs to treat Alzheimer's disease. In general, you get this coverage through private drug insurance plans, called Part D plans. Each plan covers different drugs and has different costs.

MEDICAID, INCLUDING MEDICAID FOR LONG-TERM CARE

Medicaid is a public health insurance program for people of limited means administered by the state and financed jointly by state and federal funds. Medicaid is the single largest source of health coverage in the United States. It

will pay for many medical services including inpatient hospital care, outpatient hospital services, laboratory and x-ray services, skilled nursing care, nursing home care and home health services.

Medicaid rules and regulations may vary considerably from state to state. It is not unusual to confuse Medicaid and Medicare programs since both were started about the same time, deal with health care, and sound similar. The programs are very different, however. One of the primary differences between the two programs is that Medicaid is based on financial and other eligibility standards. Medicare is a federal program and is based primarily on age and on work history, rather than income.

To be eligible for Medicaid in Hawai'i, you must be a resident of the state of Hawai'i, a US national, citizen, permanent resident, or legal alien, in need of healthcare/insurance assistance. Your financial situation would be characterized as low income or very low income. You must also be in one of the following groups:

- Pregnant, or
- Responsible for a child 18 years of age or younger, or
- Blind, or
- Have a disability or a family member in your household with a disability or,
- Be 65 years of age or older.

To apply go to: <https://medical.mybenefits.hawaii.gov/web/kolea/home-page>

Or call Med-QUEST Enrollment Services Section at 1-800-316-8005 toll-free if you have health plan enrollment and eligibility questions. TTY users, call 1-800-603-1201 toll-free.

Qualifying for Medicaid Long-Term Care

Many older adults are concerned about who would care for them in case they become seriously ill or disabled. Although most long-term care is provided by unpaid family members and friends, people often need more help as they get older and frailer or when an illness or a disability gets worse. Professional help

might be a choice. But a greater concern might be how to finance long-term care.

In general, there are three ways to finance long-term care:

- Personal money, such as savings and investments
- Long-term care insurance
- Medicaid (or other government benefits)

Since Medicaid covers the high cost of long-term care, qualifying for Medicaid long-term care is very desirable. Most people who enter nursing homes do not qualify for Medicaid at first because they pay for the very high costs of this care with their personal resources or long-term care insurance. After the insurance and private funds are spent down, they may become eligible for Medicaid.

Note that, due to the extended time needed for the printing requirements for this handbook and due to logistics backlogs due to Covid 19, 2021 figures are being used. 2022 and beyond figures are expected to rise slightly but the information in this handbook should provide you with a good idea of how income and assets have an effect on Medicaid eligibility. Information about Medicaid eligibility in Hawai'i can be found at a number of websites including: <https://www.medicaidplanningassistance.org/medicaid-eligibility-hawaii/> <https://humanservices.hawaii.gov/mqd/ffs-long-term-care/>

Single Persons, Spouses and Spousal Impoverishment

When applying for Medicaid, be aware that Medicaid long-term care programs will take into consideration several factors. For example, whether a person is applying for Medicaid non-nursing home care (such as outpatient care or hospitalization) or for Medicaid long-term care; and whether a person who is applying is single or married. These are some of the factors that will affect eligibility and, if you are married, how much money your spouse may keep if you need Medicaid long-term care and your spouse remains in the community.

Some examples of Medicaid eligibility are the following:

- **If you are a single or married, and applying for Medicaid non-nursing home care:**

For Hawai'i residents aged 65 or older, or those who are officially blind or disabled, the monthly income limit is set at 100% of the Federal Poverty Guidelines. It should be noted that Hawai'i has higher Federal Poverty Guidelines limits than do the other states, with the exception of Alaska. In dollar terms, as of March 2021, an individual applicant must have income equal to or less than \$1,235 per month (\$14,820 per year) in income, and \$2000 or less in assets.

Married couples, with both spouses applying for Medicaid non-nursing home benefits, are able to have income up to \$1,670 per month (\$20,040 per year) and \$3000 in assets. There are certain assets that do not count toward these limits. These amounts are readjusted annually.

- **If you are a single applicant applying for Medicaid long-term care:**

If an individual is applying for a long-term care benefit, there is no specific income limit. Instead, there is a cost share calculation. This means that the individual will keep the first \$50 of monthly income and the rest will go to the long-term care facility. There is a \$2,000 asset limit, but certain assets do not count towards this limit.

- **If you are married with both spouses applying for Medicaid long-term care:**

Each spouse's entire income except for \$50/month per spouse must go towards cost of care. The asset limit is \$3000. There are certain assets that do not count towards this limit.

- **If you are a married applicant applying for long-term care and your spouse is in the community (see spousal impoverishment on the following pages):**

Asset limit: \$2,000 for applicant

Income limit: \$130,380 for non-applicant community spouse

The monthly income for the institutionalized spouse that is, the person's entire income except for \$50/month, must go towards cost of care. See the spousal impoverishment section for additional information about income for the spouse in the community.

- **Spending down to qualify - Medically Needy Pathway:**

Exceeding the income limits does not mean an individual cannot qualify for Medicaid. In Hawai'i, the Medically Needy Pathway (also called Medically Needy Spenddown Program) allows those who are categorically aged or disabled who would otherwise be over the income limit, to qualify for Medicaid if they have high medical expenses. They can “spend down” their excess income by paying for medical services and goods, including paying for medical bills, prescription drugs, private health insurance, and medical expenses that Medicaid does not cover. Once they have spent their excess income on medical expenses and reached an income level of \$469 per month for an individual or \$632 per month for a couple, they will be Medicaid eligible for the “spend down” period, which for Hawai'i is one month.

Spousal impoverishment

For many married couples, the cost of providing long-term care for just one spouse can cause both spouses to become impoverished. Thus, Congress has created special rules to prevent this “spousal impoverishment,” through the Medicare Catastrophic Coverage Act of 1988 (MCCA). Medicaid calls the spouse who stays in the community and not in the nursing home the “community spouse.” The spouse who is applying for long-term care Medicaid is referred to as the “institutionalized” spouse.

The MCCA helps protect against spousal impoverishment by setting special income and resource rules for married couples. The special rules only apply when a married couple consists of one spouse who needs long-term care services in a skilled nursing facility and one spouse who lives at home. The spouse who needs long-term care is referred to as the “institutionalized spouse” and the spouse who lives at home is referred to as the “community spouse.” The MCCA sought to protect the community spouse from impoverishment by allowing that spouse to retain a much larger sum of resources and income than under Original Medicaid rules.

Under 2021 standards, the Community Spouse Resource Allowance is \$130,380. If the couple’s “non-excluded resources” exceed \$130,380 then only the excess of \$130,380 will be attributed to the institutionalized spouse in determining eligibility. In other words, the institutionalized spouse may

retain \$2,000 of their own assets and the community spouse will be able to keep up to \$130,380 in assets, in addition to such “excluded assets” as the family residence, an automobile, and household and personal effects. This is dramatically different from basic Medicaid eligibility standards of \$2,000 per person or \$4,000 for a couple. Income is also examined differently under the MCCA than under Original Medicaid rules.

Income is considered to belong to the spouse in whose name the check or other instrument is made payable. However, if the check or instrument is in the name of both spouses, then one-half of the amount will be considered available to each spouse. This rule is called “attribution.” One reason this is so important is because there are limits on the amount of income the institutionalized spouse may retain.

The institutionalized spouse is allowed to keep \$50 of his or her own income each month. The rest of the institutionalized spouse’s income will be allocated between the community spouse and the nursing facility expenses.

The community spouse’s income is not considered to be available to the institutionalized spouse. Rather, the institutionalized spouse may be permitted to give some of his or her income to the community spouse. In 2021, the Monthly Maintenance Needs Allowance is \$3,259.50 for spouses in Hawai‘i. Thus, if the community spouse has income of less than \$3,259.50 per month, they can request an amount of money from the institutionalized spouse that would bring their income up to \$3,259.50. The rest of the institutionalized spouse’s income will be applied to their long-term care expenses. The level of the “spousal allowance” can vary according to the cost of living factors and changes, if any, would take place on January 1 of each year.

The 2021 spousal impoverishment standards are currently published at: <https://www.medicaid.gov/medicaid/eligibility/downloads/ssi-and-spousal-impoverishment-standards.pdf>

Home Equity

The Deficit Reduction Act of 2005 (DRA) provides for a denial of benefits for an individual who has more than a certain amount of equity value in a home. The home equity exemption in Hawai‘i in 2021 was set at \$906,000. This

restriction does not apply if a spouse, minor or disabled child resides in the home. It permits individuals to use tools such as a reverse mortgage or home equity loans to reduce their total equity. It also requires a process to waive the application of the denial of eligibility in cases of demonstrated hardship. The equity value of a home is the current fair market value (FMV), minus any encumbrance on it. An encumbrance is a legally binding debt against the home. This can be a mortgage, reverse mortgage, home equity loan, or other debt secured by the home.

Assets – Countable and Exempt

An applicant must reveal assets. Under Medicaid rules some are countable assets and others are exempt assets. Assets which include but would not be limited to cash, bank savings, stocks and bonds, and investments (including real estate) are totaled and compared against Medicaid’s resource levels, which is generally \$2,000 for a person and \$3,000 for a couple (plus \$250 for each additional person). Property held by persons in their own names such as the home, clothing, household furnishings, and appliances; one wedding and one engagement ring; one burial space per family member; the value of a funeral plan, contract, or trust; and motor vehicles are all considered “exempt” assets that a person may keep and still be eligible if he or she meets other eligibility criteria. Assets owned in certain types of trusts may also be considered “exempt.” However, in recent years, several noteworthy rules have changed relating to how Medicaid views the home property for individuals who apply for Medicaid long-term care benefits. One primary change to note concerning the ownership of a home is that a home placed in a trust is no longer considered an exempt asset.

Transfer of Assets Penalties

An application for long-term care assistance through the Medicaid program will require an evaluation of an individual’s current assets but will also require details about an individual’s or couple’s financial transactions during the sixty-month period immediately prior to the application date. This sixty-month period is referred to as the “look-back period.” Every application for long-term care assistance will require an applicant to disclose the amount of assets the individual or couple transferred during this look-back period. If an applicant reports that assets were transferred for less than fair market value during this

look-back period, the individual may have to wait a certain amount of time before Medicaid will provide long-term care assistance. This waiting period is known as the “penalty period.”

The length of the penalty period is calculated by dividing the value of all assets transferred for less than fair market value (i.e., a “gift”) during the look-back period by the state average daily cost of long-term care. In 2021 this amount is \$295 per day. For example, if the total gifts during the look-back period were \$295,000, the penalty period would be 1,000 days:

$\$295,000 / \$295 = 1,000$). The penalty period will begin once the applicant is otherwise eligible for Medicaid long-term care assistance.

An individual or a couple may gift certain assets without triggering a penalty period, but these transfers should be done with extreme caution. Even if a gift is not penalized for Medicaid long-term care planning purposes, there may be other unintended consequences. The consequences may be worse than a penalty period, and could range from unnecessary taxation, accidental disinheritance, and even being kicked out of your own home.

Note that there are certain exempt transfers. Spouse-to-spouse gifts regardless of the amounts are exempt from the imposition of any period of Medicaid ineligibility penalty. There are exemptions that apply to the family home. A home can be transferred without penalty to the following individuals:

- A spouse,
- A child under the age of 21,
- A blind or disabled child of any age,
- A sibling who has an “equity interest” in the home and who has lived in the home for at least a year before the Medicaid application is filed,
- A child who has lived in the parent’s home for at least two years before the Medicaid application is filed and who has provided services to help avoid institutionalization of the parent.

When a penalty period is assessed against an applicant, the applicant has a few options to remove the penalty. One option is to seek that the gifts be returned. Returning the gift will remove the penalty but may also cause the applicant to have too many resources to qualify for Medicaid. If the applicant

cannot recover the gifted asset, the applicant may ask for an exception based on hardship. For such hardship provisions to apply, the application of the transfer of assets provisions would need to deprive the individual of either medical care such that the individual's health or life would be endangered, or of food, clothing, shelter, or other necessities of life. Such procedure must provide for notice to recipients that an undue hardship exception exists, a timely process for determining whether an undue hardship waiver will be granted, and a process under which an adverse determination can be appealed.

Medicaid Liens and Estate Recovery Provisions

Besides a period of ineligibility, federal regulations require the state to recover Medicaid payments from medically institutionalized recipients. The State of Hawai'i now has "lien" and "estate recovery" provisions to seek reimbursement of certain medical costs paid by the state. The state recovery of medical assistance payments is made from the estates of individuals who received assistance while in a nursing facility or from individuals not in nursing facilities who received benefits from the age of 55.

The state may place a lien on the real property of a medically institutionalized individual for the amount of medical assistance received, only after there is a determination that the individual cannot reasonably be expected to be discharged from the institution to return home. This provision is, as with everything else, subject to change. If the Medicaid recipient's stay in the medical institution is likely to be permanent, based on a determination as to whether the recipient can reasonably be expected to be discharged from the medical institution and return home, the state will send a notice to inform the affected recipients that a lien may be placed on the home.

Cautions Regarding "Medicaid Planning"

There are many rules and exceptions that apply as to how the lien is to be placed and when estate recovery will be pursued. In view of the 60-month look-back period, the estate recovery provisions and the risk of liens, it is important to analyze the rules about transferring assets along with potential income, and estate and gift tax consequences in attempting to shelter assets. Medicaid laws have changed and can change again very quickly.

No one knows what the Medicaid rules will be in the future, so individuals should not rely on the information contained in this book for Medicaid planning, and be especially careful if you are considering transferring a home. Some of the saddest cases we have dealt with involved individuals who transferred their homes with the hopes of eventually qualifying for Medicaid long-term care coverage. Some made mistakes in transferring their homes and were disqualified for many years. Some have been subsequently evicted from their homes by their children, grandchildren or other relatives. Some never needed long-term care and were unable to get their homes back.

We recommend that individuals consult an elder law or estate-planning attorney before making transfers of any assets for less than fair market value. Otherwise, they should at least check with the Med-QUEST Division of the Department of Human Services about transfer penalty provisions when trying to qualify for Medicaid.

Medicaid Appeals

If an application has been denied or not processed within the required period of time, or if there has been a refusal to pay for medical services, or if there is a determination that the person is no longer eligible for Medicaid, under federal law the individual is entitled to written notice of any such decision. This notice should inform the individual of the right to file a request for a “fair hearing” within 90 days from the date of the notice. Once the individual has filed a request, a decision must be made within 90 days of the filing. If the decision is unfavorable, the government is required to provide information on how the individual may further appeal the decision, including appeals through the courts.

CHAPTER 4

DECIDING WHO CARES AND PROTECTS?



CHANCES ARE . . .

Chances are you will be a caregiver or care recipient, and in some instances, maybe both. The Covid-19 pandemic has demonstrated that caregivers will need to be adaptive and move quickly to address a myriad of issues, such as health care, financial and legal issues. Social isolation during the Covid-19 pandemic proved to be especially challenging and, in some cases, damaging.

Even under “normal” circumstances, caring for an older person with a disability (or for more than one person) can be difficult, stressful, and sometimes thankless, especially for a family caregiver. If you are a family caregiver, the person being cared for may be unappreciative, may be demanding, abusive, need constant supervision or may not even recognize you. You may not have enough time to sleep, much less take care of your own personal matters. If you do not have the proper tools, training, finances, support and respite, you may risk neglecting yourself as well as the person(s) being cared for. Some caregivers who become desperate may give up and may even abandon the person they are caring for if they do not know what else to do. This can lead to actual abuse of the person being cared for, allegations of abuse filed against the caregiver, or even abuse directed at the caregiver.

Just as care receivers can be victims of abuse or neglect, caregivers can be victims of stress, anxiety, and caregiver burnout. This can happen when the caregiver has little support in giving care, has few financial resources, and is beset by the enormity of giving care to an elder person who may be sick or bedridden or suffers from dementia and requires constant supervision. Other family members may not be willing or able to help. A common example is a situation where a sibling who for years has not been caring for a parent flies in from another state and attempts to “take over” the situation. Family conflicts are not uncommon and can be detrimental to the health and the well-being of both care recipient and caregiver. Research has shown that caregivers often are at increased risk for depression and illness. By acknowledging the reality that being a caregiver is filled with stress and anxiety, and understanding the potential for burnout, caregivers can be forewarned and guard against this debilitating condition. It cannot be said too often, that the best way to be an effective caregiver is to know your limitations and to take care of yourself first.

Caregiver Services

Sometimes, older persons require help outside of health services. Household chores, transportation, yardwork, grooming, and meal preparation are all areas in which people may need assistance as they grow older. The local County Offices on Aging, which are the Hawai'i County Office on Aging, the Kaua'i County Agency on Elderly Affairs, the Maui County Office on Aging, and on O'ahu, the Elderly Affairs Division of the City and County of Honolulu, may be able to provide information about various social services. They can be reached at:

- Hawai'i County Office on Aging: (808) 961-8600;
Kona: (808) 323-4390
- Kaua'i County Agency on Elderly Affairs: (808) 241-4470
- Maui County Office on Aging: (808) 270-7774
- O'ahu, the Elderly Affairs Division of the
City and County of Honolulu: (808) 768-7700

Caring for Native Hawaiian Persons

Older persons of native Hawaiian ancestry may be able to access caregiving services provided by the *Kumu Kahi* (Elderly Services) department of *Alu Like*

on O‘ahu and the neighbor islands. *Ke Ola Pono No Nā Kūpuna (Good Health and Living for the Elderly)* provides nutritional and supportive services for native Hawaiian persons 60 years and older. The Native Hawaiian Caregiver Support Program helps families caring for a n older native Hawaiian person, 60 years and older with a chronic illness or disability. It also provides services to native Hawaiian grandparents or older relatives caring for children age 18 and under who meet certain criteria. A birth certificate is required or proof of age and ethnicity. The phone number to the *Alu Like Kumu Kahi* Elderly Services central office is (808) 535-6700.

Long-Term Care Facilities

When family caregiving becomes too much to handle, sometimes it is necessary to use the services of a long-term care facility that provides various levels of care, such as custodial, intermediate-level and skilled-level care services to persons who require nursing services. Descriptions, comparisons and ratings of nursing homes certified by Medicare and Medicaid are provided at the “Nursing Home Compare” website: www.medicare.gov/NHCompare

You can search for long-term care facilities on the website by specific geographic areas. Adult Residential Care Homes (ARCH), Expanded ARCH, and Foster Family Homes provide shelter, supervision, and care for persons needing help with daily living activities. Most ARCH and Expanded ARCH facilities are private homes in residential communities, licensed for up to 5 persons. Some offer specialized care, such as for those with Alzheimer’s disease. Costs vary depending on amenities and amount of care provided. When choosing an ARCH facility, it is a good idea to interview the caregiver and residents, observe the condition of the physical and social environment, understand the rules on visiting hours and so on. You may also want to inquire about the facility’s most recent survey/inspection findings done by the licensing agency.

The State of Hawai‘i, Department of Health, Office of Health Care Assurance provides a list of certified long-term care Nursing Facilities and Care Homes in the state, including location and available beds at: <https://health.hawaii.gov/ohca/state-licensing-section>

Also, for concerns about or assistance in the investigation and resolution of problems or complaints about the care or services provided in long-term care facilities located in Hawai'i, the Hawai'i State Long-Term Care Ombudsman can be contacted at (808) 586-7268.

Nursing Home Consumer Caution

Caregivers should also be aware that some health care facilities may try to take advantage of their vulnerabilities and the pressure they are under to force them to provide care for their family members. To add to the caregiver's problems, some health care providers, especially long-term care facilities, may request that caregivers sign documents to personally assume financial responsibility for the person receiving care. This is often done in the admission process when emotions are mixed and time is limited. If you sign such a document, you may be required to pay out-of-pocket any expenses not paid by insurance, government benefit programs, or the care recipient's own assets. You should understand that in Hawai'i there is generally no requirement for you to be responsible for any person other than your spouse or minor children unless you do so voluntarily. Federal law generally prohibits long-term care facilities from requiring you to assume such personal financial responsibility. The loophole that some facilities use is to ask you to sign the document "voluntarily."

Always have these types of documents reviewed by an attorney before signing them. Read and review the document and seek out those provisions that make you financially responsible and cross them out if you find them unacceptable. Also, when signing documents on behalf of another, it is usually wise to make it clear that you are signing as a legally authorized person such as the guardian, trustee or agent under a power of attorney and not in your personal capacity. If your care receiver does not have a power of attorney or trust and is still mentally incapacitated, discuss getting one or both of these before it is too late.

ELDER ABUSE

The Covid-19 pandemic has been particularly harmful to older adults, and there has been a massive increase in reports of elder abuse during the pandemic. Reports of elder abuse range from financial scams to incidents of family violence, with public warnings issued accordingly from the Federal Trade

Commission and the American Bar Association. Well before the pandemic, elder abuse was described as a “hidden epidemic” in our society and it just got worse. Elder abuse can be defined as physical or mental mistreatment or injury or neglect that harms or threatens an elderly person. It is often distinguished from ordinary crimes directed against elderly persons by the repetitive character of the acts, often committed by a relative or other caregiver. While there is no specific Hawai'i law that addresses elder abuse, various laws provide protection to vulnerable and dependent adults, including elderly persons.

Some Causes of Elder Abuse

There are many causes of abuse. Some abusers purposefully hurt an older person, especially if the older person is defenseless. These abusers may be evil, violent, mentally disturbed, or may abuse drugs or alcohol. Some use abuse as a means of control over the older person. Others use abuse as revenge or “pay back” for abuse that the older person may have committed in the past. Poverty or greed can cause abusers to steal money or property from their victims.

Abuse and neglect of older persons take place most commonly in the victim's home and in institutions such as nursing and care homes. In the home setting, the person who cares for the victim may often be the abuser, someone who often has repeated contact with the victim and has the opportunity to commit the abuse. Spouses, children, grandchildren, nieces and nephews, siblings, neighbors, friends and hired caregivers are examples of people who may be abusers. In an institution, abuse is most often committed by employees on those who are physically or mentally incapacitated. Abused older persons often endure the abuse for fear of losing whatever support the abuser may be providing. They may feel helpless and feel they have nowhere to go or no one to turn to. If you feel you are being abused or know someone who is being abused, help is available.

Older women who tend to live longer and make up the largest demographic in the world are more prone to abuse. Abuse toward women may be different from abuse toward men. Often there is domestic violence, intimidation or marginalization. Bullying might happen in the laundry room or the parking lot of

the residential building, or management might favor others. Older women may be more isolated and poorer as family and friends move away or die.

The National Institute on Aging at <https://www.nia.nih.gov/health/elder-abuse> identifies a number of different types of elder abuse such as the following:

- Physical Abuse—the use of physical force that may result in bodily injury, physical pain, or impairment;
- Sexual Abuse—non-consensual sexual contact of any kind with an elderly person;
- Emotional or Psychological Abuse—the infliction of anguish, pain, or distress through verbal or nonverbal acts;
- Neglect—the refusal or failure to fulfill any part of a person’s obligations or duties to an elderly person;
- Abandonment—the desertion of an elderly person by an individual who has physical custody of the elderly person or by someone who has assumed responsibility for providing care to the elderly person;
- Financial/Material Abuse—the illegal or improper use of an elderly person’s moneys, funds, property (including an elderly person’s home or other real estate), or assets; and,
- Self-Neglect—a self-behavior that threatens the elderly person’s health or safety.

Financial abuse and exploitation can happen to anyone and as previously indicated, there was a massive increase in reports of elder abuse during the pandemic. Abusers can be charming. They often pretend to be your friend and pressure you into giving them gifts. They may even say they are doing you a favor. They may be strangers or even your own family. Trust your instincts. Do not be fooled. Ask questions. Do not sign anything you do not understand. Get advice from your bank, an attorney, or financial advisor before you commit yourself to any course of action involving money and other assets.

Financial exploitation can include theft of cash, abuse of a power of attorney, misuse of ATM or credit cards and withdrawals from joint bank accounts, misappropriation of pension and benefit checks, illegal property transfers, and a variety of frauds and scams. Reverse mortgages and home equity loans can serve the purpose of providing cash not only to you, the homeowner, but also potentially to the abuser. Unless you understand how these programs work and

are financed, be careful about encumbering your home with debt, especially if you suspect that the proceeds are not going to be used for your benefit.

Identity Theft

Identity theft occurs when someone uses your personal information without your permission to commit fraud and other crimes. Mail and garbage theft is a common way of illegally obtaining your personal information. When thieves steal and use your name, Social Security number, credit card number, checking account number, or other identifying information, you may be sued for moneys you do not owe and you may be refused credit, housing, and bank loans. You may even be accused of a crime you did not commit. Even if it is not your fault, you may have to spend much time and money to clear your name and credit record.

Helpful Tips

- Do not give out your Social Security number without a good reason;
- Shred your personal bank checks and credit card receipts before disposing them;
- Be suspicious and careful if unsecured websites ask you for personal information which may lead to identity theft;
- Close any accounts that you think may have been tampered with;
- If you feel you have been a victim of Medicare fraud, the Senior Medicare Patrol (SMP) under the Executive Office on Aging can assist Medicare beneficiaries, their families, and caregivers; call O'ahu (808) 586-7281 or toll free: 1-(800) 296-9422;
- Visit the Federal Trade Commission (FTC) website at <https://www.identitytheft.gov/information> to obtain information about identity theft, fraud, scams or unfair business practices and get a recovery plan.
- If you are a victim, file your complaint with the FTC at: <https://www.identitytheft.gov/>

You can also contact one of the three major credit bureaus listed below to place a fraud alert and to obtain a copy of your credit report (sometimes fees may be charged). The credit bureau you contact will inform the other two credit bureaus of your fraud alert. An initial fraud alert makes it harder for an identity

thief to open more accounts in your name. (Be forewarned that call wait times may be quite long.)

- Equifax
Equifax.com/personal/credit-report-services
- Experian
Experian.com/help
- TransUnion
TransUnion.com/credit-help

Another type of elder abuse is “caregiver neglect,” described as 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; and
- Protect the vulnerable adult from abuse by third parties.

In addition to caregiver neglect, there is “Self-neglect,” which occurs when a vulnerable adult’s inability or failure, due to physical or mental impairment, or both, to perform tasks essential to caring for oneself, include but are 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; or
- Managing financial assets with respect to the above; and,

- Lacking 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.

Self-neglect may also happen when vulnerable people are forced into or choose lifestyles that may seem strange to the observer. Some older persons may be too poor to take proper care of themselves. Others may exhibit unusual behavior due to a physical or mental illness, over or under medication, malnutrition, psychological changes, depression or substance abuse. Sometimes people reach the stage where they seem to be causing harm to themselves and appear to need some kind of protection. Deciding to intervene in individuals' lives because of their eccentricity or self-neglect involves legal, ethical, and practical considerations. Lack of specific laws addressing elder abuse, plus concepts of civil rights, autonomy and self-determination very often limit the ability of concerned individuals and agencies to intervene. Sometimes the only recourse is to offer social or legal services or to attempt to persuade the people to change their lifestyle. As discussed below, the State of Hawai'i has authority to help protect certain vulnerable persons from self-neglect as well as other forms of abuse.

LAWS TO PROTECT OLDER PERSONS

As a caregiver, you will have a responsibility to protect your care recipient from abuse, neglect and exploitation. While no specific law in Hawai'i addresses "elder abuse," a wide range of laws can be used to protect abused older persons. The Hawai'i Penal Code provides criminal penalties for crimes against all persons in Hawai'i.

Frequently, elder abuse can be considered criminal and upon conviction, enhanced penalties may be sought by the prosecutor for the crime directed against an older or vulnerable person. There is a trend in law enforcement to establish specialized units to address crimes directed against older persons with prosecutors often leading the way. For example, there is an Elder Abuse Justice Unit (EAJU) in the Department of the Prosecuting Attorney of the City and County of Honolulu. They can be contacted at (808) 768-7400 see also: <https://honoluluprosecutor.org/elder-abuse-justice-unit/>

Adult Protective Services Law

The Hawai'i Adult Protective Services (APS) uses the term, "vulnerable," in defining who would be covered under this law. Note that this is not an "elder abuse" law but provides certain protections to vulnerable individuals in Hawai'i who are 18 years of age or older. The provisions of the Adult Protective Services law require certain persons who, in the performance of their professional or official duties, know or have reason to believe that a vulnerable adult has been abused and is threatened with imminent abuse, to promptly report the matter, orally, to the Department of Human Services (DHS). The Adult Protective Services (APS) Unit of the DHS oversees reports of suspected abuse. APS is required to investigate reports of alleged abuse against a vulnerable adult and has the authority to prevent further abuse. In doing its investigation, it is entitled to have access to the allegedly abused vulnerable adult and may seek the assistance of the police to gain access. If abuse is discovered, DHS must take action to prevent further abuse. It should be noted that DHS can only act with the consent of the victim unless it obtains court authorization to provide necessary services.

Under this law a "vulnerable adult" is 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 that person's own care or resources; carry out or arrange for essential activities of daily living; or protect that person from abuse.

Guidelines for mandated reporters are found at: <https://humanservices.hawaii.gov/ssd/files/2015/10/Guidelines-for-Mandated-Reporters.pdf>

Long-Term Care Ombudsman

Hawai'i's Long-Term Care Ombudsman/Advocate Law which grants investigative and access authority to the Long-Term Care Ombudsman. As an independent and politically neutral examiner, the Ombudsman receives, investigates and resolves problems with or complaints against long-term care facilities. Personal data relating to a complaint is treated as confidential and will not be released by the Ombudsman without written permission of the patient/resident or legally authorized representative.

A complaint can be lodged by anyone, including organizations, friends, staff, or anonymous persons. It is a crime to retaliate against any patient or resident who files a complaint with the Ombudsman. Persons in residential long-term care facilities, care homes, and boarding homes in Hawai'i are protected by this law. Investigation begins as soon as possible after the complaint is received. If verified, the facility's staff is asked to make corrections or provide a prompt response. The Ombudsman may also involve other responsible agencies.

Nursing Home Abuse

If you have made the difficult decision to place a family member in a nursing home, you should visit often and monitor your family member and the living environment. Take particular note of any sudden changes in your family member's appearance or demeanor, which may signal that some sort of mistreatment is taking place by the staff or another resident. Your family member may be hesitant or unwilling to speak about these abuses, because of embarrassment or fear of retaliation. If you suspect that your family member has been abused or mistreated in a nursing home, or has suffered any type of abuse, contact the Long-Term Care Ombudsman, APS or the Department of the Attorney General Medicaid Investigations Unit. You may also want to contact an attorney if you are seeking damages.

Other Interventions and Remedies

The Hawai'i Disability Rights Center can be contacted at (808) 949-2922. It may be able to assist certain disabled victims. Also, domestic violence organizations may be able to assist victims who are abused by household members. Private legal remedies, including actions for breach of contract, and tort and civil fraud may also be pursued.

You can protect yourself from an abusive individual by obtaining a "Temporary Restraining Order" (TRO) from the District or Family Court of the Hawai'i State Judiciary. The Family Court will hear cases in which the abuser is a relative, former spouse, dating partner, someone with whom you have had a child or someone with whom you have lived. Otherwise, the District Court may be able to hear the case. In all instances, you will need to fill out specific forms (available from the Clerk of the respective Court) to give the court information on the alleged abuse and certain contact information. You will also need to

participate in a hearing on the matter and may need to pay a filing fee. The TRO will be effective when it is served.

If you are in danger or feel threatened, leave your home if it is unsafe. Get medical attention if you have been injured. Report the abuse to Adult Protective Services at (808) 832-5115 to help with your safety and protection. In an emergency, call 911 for help. Should you do so, try to stay calm and clear about the address or location of the emergency so that you can be found and helped. Do not be ashamed to seek help if you are a victim.

HIRING A CAREGIVER

Caregivers take care of children, other adults, most often parents, spouses, friends or relatives, and help with many things such as: bathing, bill paying and banking for finances, shopping, preparing meals, toileting, eating and medications. To better provide for care and to prepare for the worst, the care receiver should have the following legal documents in place:

- Advance Health Care Directive that names a health care agent and that provides individual instructions for health care;
- POLST (Provider Orders for Life-Sustaining Treatment);
- Powers of Attorney or other instruments to allow an agent access to private information, manage property and financial resources;
- Will and/or Trust;
- Written instrument to control disposition of remains.

And the following important information should be kept handy:

- Medicare or Medicaid information;
- Valid personal ID such as a current passport, driver's license or state ID;
- REAL IDs will be necessary for travelers within the United States by May 3, 2023. Your driver's license or state identification card will need to be REAL ID-compliant if you want to use it to fly within the U.S. If your license or state ID is not compliant, and you don't have another acceptable form of identification, you will have trouble getting through airport security.

- Social Security card. If you need to order one, visit:
- Name and phone number of physician or other health care provider;
- List of emergency numbers;
- List of who to contact such as family members.

As “aging in place,” that is, remaining in your own home and not moving to assisted living or a retirement community, becomes more popular, hiring a caregiver to help with the many tasks and responsibilities makes sense. For more about aging in place see the last topic in this chapter.

Many families have difficulty in finding a qualified and trustworthy caregiver at an affordable price. While abuse, neglect, theft and financial exploitation can happen with any caregiver, professional home caregiver agencies normally have the resources to provide bonded and insured, trained, and pre-checked caregivers. Further, such agencies can usually provide short-notice and continuous care with back-up caregivers, as necessary.

Although agencies may be more costly than hiring caregivers on your own, they provide services that may save you needless worry. For example, they may be better suited to screen applicants and terminate an unsuitable person. They are responsible for payroll, taxes, insurance and all the duties of running a business. Most of all, much of the stress is removed from being a caregiver.

If you hire your own caregiver you may save some money, since you will cut out the built-in overhead costs associated with a business enterprise and its profit objective. But, as an employer, you will need to comply with employment laws and payroll taxes.

To help employed caregivers, a pilot program called, *Kupuna* Caregivers Act, was launched in 2018. It made Hawai'i the first state in the nation to offer money to caregivers who also work full-time. The purpose of the act was to help ease financial stress so that the caregivers would not have to give up their jobs. The *Kupuna* Caregivers Program pays employed individuals who are also caring for a loved one by providing support services that allow their loved one to remain at home so that the caregiver can remain employed. Through this program, up to \$350 per week may go towards the cost of long-term senior care and services, such as adult day care, in-home personal assistance,

respite care, and more. Since it is not an entitlement program, there may be a waitlist for program participation.

For more information about both programs call ADRC (Aging and Disability Resource Center) at (808) 643-2372 to apply or the ADRC TTY line, (808) 643-0899.

Types of Caregivers

This section looks at caregiving from the perspective of an individual who may be in need of a caregiver. If you are thinking about the type of caregiver you need, of course it will depend on your own particular situation and the types of services and the levels of services required. You may or may not need round-the-clock services. You may or may not need to have household or chore services. You may or may not need close supervision for a frail or vulnerable or physically or mentally disabled person. You may or may not need to have intensive home health care services. Each situation is different and there is no set answer.

There are differences even among home health care providers. For example, Medicare-certified home health agencies are licensed by the State of Hawai'i and are reimbursed by Medicare. They provide part-time, intermittent, skilled nursing services with at least one other therapeutic service ordered by the physician (e.g., occupational, physical and speech therapy). Private duty service providers are hired by individuals to provide services that are not reimbursed by Medicare.

If you need to hire a home health care provider, one way to get assistance in locating an appropriate licensed provider is to use the services of a home care association such as the Home Care and Hospice Division of the Healthcare Association of Hawai'i (www.hah.org) Note that physician orders are required for home health services to qualify for Medicare reimbursement.

Using a Professional Service Agency

If you decide to hire a professional service agency, check to see if:

- The agency is registered/licensed with the State Department of Commerce and Consumer Affairs;
- The agency is Medicare-certified if you will be seeking Medicare reimbursement;
- The agency has a record of complaints or not;
- The agency/supervisor is available by phone at all times;
- The agency has written policies and procedures pertaining to patients' bill of rights, services, costs, payment plans, malpractice/ injury, thefts, unacceptable behavior, and disputes;
- Employees are insured and bonded;
- Employees are trained;
- Employees are screened for health, background and criminal histories;
- References for employees are available.

Although the cost of hiring a private caregiver may be significantly lower than using a licensed and certified caregiver agency, there are certain drawbacks. For example, Medicare will only provide reimbursement for eligible services provided by a Medicare-certified home health care agency. Private health insurance plans may have the same policies.

Benefits and Burdens of Being an Employer

Hiring your own caregiver may be better suited to your circumstances. You become the employer and thus you can demand greater loyalty and can provide greater direction to an employee that you select yourself. While there are advantages to being an employer, you also take on the responsibility for hiring, paying and supervising the caregiver. The responsibilities include those typically associated with running a business which hires people.

- First, you have to find your own qualified caregiver. This may mean advertising in a newspaper or the Internet, interviewing candidates, checking on references, checking on driver's licenses and medical records, and even performing abuse/criminal record background checks. You will need to get permission/privacy waiver documents from the prospective employee for some of these. Be sure to screen well. Abuse abounds.
- Second, you have to enter into an employment agreement. This usually includes a written contract which contains such matters as the job

description, work schedule, back-up help, time off, wages, meals, use of automobile and other equipment, work rules dealing with such issues as alcohol use, smoking, personal phone use, and termination policy, including prior notification, if any. If you do not have a written agreement, you may be setting yourself up for trouble.

- Third, you have to supervise and manage your caregiver. This usually includes providing necessary instructions, training, orientation, demonstration of preferred techniques, and testing emergency responses. It also includes providing appropriate discipline, including dismissal, reporting to protective services agencies, and even bringing criminal charges.
- Fourth, you have to comply with federal, state, and local laws, regulations, and ordinances. These include legal eligibility, immigration assurance, wage and hour compliance, employment/ labor practices, tax and insurance matters. It also includes obtaining tax identification numbers, withholding federal and state taxes, and paying Social Security/Medicare (FICA) and unemployment taxes. It further includes obtaining workers' compensation and liability insurance. You will be required to fulfill federal and state record-keeping requirements on each employee to ensure compliance with all of these matters.

Even if you hire a caregiver for a short period of time, you will be required to comply with federal and state “nanny taxes” which are technically called “Employment Taxes for Household Employees,” if wages to any caregiver exceed \$2,300 in 2021.

Checklist for Employers

At the end of this overview is a “Checklist for Employers” which will give you a head start in the process of engaging caregivers. The Internal Revenue Service (IRS), Social Security Administration as well as the State Departments of Taxation and Labor can provide you with valuable information, instructions, and required forms for employers. The Immigration and Naturalization Service (INS) can provide information about work registration requirements and legal documentation. A great resource to get you started is the Department of Commerce and Consumer Affairs’ Consumer Resource Center.

Caution

You may be tempted to engage a so-called independent contractor” to try to get the best of both worlds by avoiding the extra cost of a professional caregiver agency while also avoiding the effort of employing a caregiver. You should be aware that employment and tax laws are written in such a manner to presume that a person is an employee and not an independent contractor if the person engaging the services can control what is done, when it is done and how it is done. If you have the right to control the method and result of the service, you are probably an employer. It does not matter whether the person is full or part-time.

In Hawai'i, every individual or organization, which becomes “an employing unit,” must file a status report (Form UC-1, “Report to Determine Liability”) with the Unemployment Security Division of the State Department of Labor within twenty days after hiring an employee. You may call the Business Action Center of the Department of Commerce and Consumer Affairs which will supply you with forms for registering your business. Also, the IRS has a very helpful guide (Publication 926–Household Employer’s Tax Guide), which you should read before hiring a caregiver. There are agencies that can help you fill out forms and file necessary taxes for a fee. Of course, your attorney can answer your questions and assist you in this matter.

Insurance

Whether you engage a professional caregiver agency, hire an employee or perhaps engage an independent contractor, make certain that you check with your insurance agent to ensure that your homeowner, automobile and other liability policies cover the caregiver in your home. If you are going to permit or request the caregiver to drive your automobile, check to make sure that the person has a valid driver’s license and check whether that person has been convicted of serious traffic offenses. Always check with your automobile insurer to see if your policy covers the caregiver. Further, look into having the caregiver bonded for your protection.

Caregiver's Contract

Agreements and arrangements made with a caregiver should be documented in a contract. A contract will set the terms and conditions, include a description of services to be provided, fees and dispute resolution. Contracts can avoid misunderstandings as well as provide documentation of the respective rights and responsibilities of all the parties involved. Consult with an attorney if you have questions about any contract.

Criminal History Record Check

It is always a good idea to consider requesting a criminal history record check on prospective employees, especially if they are not well known to you. The Hawai'i Criminal Justice Data Center (part of the Department of the Attorney General) is responsible for the statewide criminal history record information system. You may search for, view, and purchase an individual's conviction information online at <https://ecrim.ehawaii.gov/>

You can also access this information plus related services such as searches for sex offenders, information about individuals or businesses licensed by the Professional & Vocational Licensing Division and searches for all businesses registered in the State of Hawai'i at: <https://portal.ehawaii.gov/home/online-services/ecrim/>

Note that arrest records which have resulted in convictions (the individual has been found guilty) are considered public record. Arrest records which have resulted in non-convictions or are still pending, are considered confidential and not available to the general public.

CHECKLIST FOR EMPLOYERS

1. RECRUITING

- Non-discriminatory advertising
- Personal information permission/Privacy waiver
- Prior employment reference check
- Personal reference check
- Credit check
- Medical/health check (including contagious diseases)
- Abuse report check
- Criminal records history check
- Interview questionnaire

2. EMPLOYMENT AGREEMENT

- Enforceable legal contract format
- Job description
- Work schedule
- Back-up help schedule
- Time-off schedule
- Wages
- Meals
- Work rules (e.g., smoking, alcohol, personal phone calls, visitors, etc.)
- Acceptance and exchange of gifts (prohibition with person cared for to avoid theft and undue influence questions)
- Termination policy

3. SUPERVISING

- Introduction to person cared for, family, neighbors, and professionals
- Training (content, resources, materials, and courses)
- Orientation to job, home, support facilities and responsibilities
- Demonstration of preferred manner of commonly performed tasks
- Testing of emergency notification and substantive procedures
- Performance reports
 - Disciplinary options
 - Counseling
 - Warning
 - Reporting to Adult Protective Services Unit, Department of Human Services

- ___ Reporting to Police
- ___ Dismissal

4. TAXES, LAWS, REGULATIONS, INSURANCE

- ___ US Citizenship or legal authorization to work: INS Form I-9
- ___ Minimum wage determination
- ___ Federal Income Tax Withholding: IRS Form W-4
- ___ Federal Wage and Tax Statement: IRS Form W-2
- ___ State Wage and Tax Statement: IRS Form W-2
- ___ Employer Identification Number Form SS-4
- ___ Federal Insurance Compensation Act (FICA): IRS Form 1040, Schedule H
- ___ Social Security
- ___ Medicare
- ___ Federal Unemployment Tax Act (FUTA): Form 940
- ___ State Unemployment Tax: Form UCB-6
- ___ State of Hawai 'i Business Registration: Form UC-1
- ___ Employee Records
 - ___ Name: _____
 - ___ Address: _____
 - ___ Phone Number/Cell: _____
 - ___ Date and Place of Birth: _____
 - ___ Social Security Number: _____
 - ___ Driver's License Number: _____
 - ___ Date hired: _____
 - ___ Date discharged: _____
 - ___ Dates and amounts of wages: _____
- ___ Copies of contracts, other agreements, records checks, performance reports, termination notice, other communications;
- ___ Copies of Tax, FICA, and Insurance documents and filed forms;
- ___ Homeowner's, automobile, and liability insurance policies;
- ___ Employee bond.

COPING WITH DEATH AND DYING

Many families faced the prospect and the reality of death during the Covid-19 pandemic. People go through different emotional stages when confronted with death and dying. Denial, anger, bargaining, depression, and acceptance are mentioned as stages that a person experiences as a way of dealing with the fear and anxiety associated with dying. Counselors say that a person usually goes through each of these emotional stages in some degree or another before a resolution is made and a person is able to return to a somewhat normal life. Situations of death and dying affect each person differently and going through the emotional stages takes different lengths of time and varies in intensity for each person. Resources are available to support individuals going through the process of death and dying.

Hospice Care

The concept of hospice started in the 11th century as places of hospitality for the sick, wounded, or dying, as well as for travelers and pilgrims. The modern concept of hospice is based on a belief that death is a part of life and concentrates on relief from pain and support for the individual's emotional and spiritual needs. Hospice emphasizes palliative rather than curative treatment for the incurably ill and is given not only in such institutions as hospitals or nursing homes, but also in personal residences to those who choose to die in their own homes.

Most hospice care is covered completely by insurance, Medicare, or Medicaid. Room, board, and medications are not covered. Hospice workers and volunteers are trained to help the dying person, relatives, and friends to prepare for the death process as well as the actual death moment. The hospice program can also provide immediate emotional support for the survivors.

Kokua Mau is an organization that provides information and resources about end-of-life care. They can be contacted at (808) 585-9977 or to view their website or to download their forms go to: www.kokuamau.org

Steps to Take Upon Death

When death occurs, survivors will need to take steps to decide who to notify, what to do with the body, what type of ceremony or memorial to have and, if any, what services and merchandise to purchase.

When Death Occurs At Home

If the care receiver dies and is not enrolled in a hospice program and if you have not made previous arrangements with the attending physician, call 911. The operator will ask if it is an emergency. Explain that a death has occurred and the circumstances. A medical examiner, paramedic, or coroner will be sent to the address to verify that a death has occurred. You can make arrangements with a funeral home or mortuary to remove and store the body until it can be buried or cremated. The morgue (Medical Examiner Facility) will normally not store the body unless there is evidence of a violent or suspicious death, the body is unclaimed or the body has a contagious disease.

The police may need to be notified if the death was unattended or unexpected. If the death was expected and a physician was attending the individual, the physician can inform the survivors what to do. Typically, prearrangements will have been made and the survivors call the prearranged contact at the funeral home or mortuary to take the body. If you are a survivor who will be taking charge of making decisions, you may want to notify relatives, close friends and business associates and arrange for funeral or memorial services. For deceased veterans or spouses of veterans, contact the U.S. Department of Veterans Affairs to see if they qualify for benefits at www.va.gov

When Death Occurs in a Hospice or Medical Facility

If the death occurs in a hospice or medical facility, the hospice and medical personnel and volunteers can help guide the survivors. If death occurs in another type of health care facility, appropriate procedures, including governmental agency notification, will already be in place.

When a nursing home, hospital, doctor, or the police notify the survivor that a death has occurred, the survivors are usually instructed to contact a funeral home or mortuary to make arrangements for the disposition of the body.

Problems have occurred when two different parties have different opinions about who should be in charge of disposing the body or what should be done with the body. Hospitals will generally release the body to the “next of kin” or a family member such as the spouse, reciprocal beneficiary, civil union partner or other closely related family member.

Sometimes, when there is no legal next of kin, funeral homes will not honor the wishes of the unrelated party. Funeral homes will generally follow the directions of the next of kin unless there is evidence specifying another party. To avoid conflicts in an emotionally charged time, it would be best to put into writing a person’s choice regarding who will make decisions regarding the disposal of the body. This can be done in a will and expanded upon in a letter to the personal representative but, as previously mentioned in both chapters 2 and 4, it may be best to execute a written instrument to control disposition of remains before a notary public.

Funeral and Memorial Plans

Funeral or memorial plans can be very simple or they can be very elaborate. Of course, pre-planning, which includes a pre-chosen funeral home or mortuary and pre-paid services, would be helpful in most situations. Many people are choosing to belong to a memorial society which is a non-profit organization dedicated to achieving dignity, simplicity, and economy through pre-planning. If you are a veteran, ask the U.S. Department of Veterans Affairs for advice concerning advance funeral and memorial arrangements. If you are receiving public assistance, you should also know that the state may pay for certain expenses relating to the disposition of your body. Your plan, accordingly, may be as simple as letting your survivors know to call the Hawai’i State Department of Human Services for assistance upon your death.

Funeral and Memorial Services

There have been highly publicized problems about the funeral industry on the mainland and in Hawai’i. When you consider that funeral-related decisions are usually made in just a few hours, you can see why people are sometimes exploited. Good business practices should be followed by you as a consumer in getting the contract for services in writing, knowing what you are paying for, knowing which services are not necessary, and seeing that all these services

are performed as agreed. Beware of such practices as substitution of one casket for another or charging for services you do not need such as thank you cards, if you are providing your own, or a flower car if there are no flowers, pallbearers who were not requested, or charging for clothing for the deceased that you are providing. Plans are often made according to the prescribed religious funeral or memorial rites of the deceased and the funeral director, your minister, priest, rabbi, or spiritual advisor can help with the plans.

Funeral plans can include burial, entombment or cremation. Embalming is a method of preserving the appearance of the body for open viewing. Embalming is not always required and is usually unnecessary if the body is to be cremated within a certain time period. The scattering of ashes can be accomplished informally or can involve elaborate ceremonies. According to the state Department of Land and Natural Resources, no environmental permit from the Health Department is required to scatter cremated ashes on land, sea or from the air, but it should be done discreetly and some distance away from the general public. Also note that ashes are not allowed to be scattered within a state forest preserve or watershed area, or on state or federal property. While, generally speaking, there is little regulation of scattering of ashes in Hawai'i, there may be regulatory restrictions in other jurisdictions.

The funeral home or mortuary may be able to provide you with information about scattering of ashes. They may discourage such a practice, even if it is legal, if they have their own plan that they may wish to sell to dispose of the ashes.

Be aware that payment for the costs of a funeral may need to be made in advance by those requesting the service. This can be financially difficult for families who do not have immediate access to the deceased's estate.

Memorial services differ from funeral services. Traditionally, funeral services are those which are held in the presence of the body and may include a viewing. Memorial services are held without the body and are usually less costly. Often, memorial services are held when friends and family cannot immediately meet after a death. Other things to consider for a funeral or memorial are the music, the eulogy, the gathering place, food, readings, obituaries, and pallbearers or attendants.

Making Your Own Preparations

When purchasing a funeral plot, you may wish to address some considerations:

- Who owns the cemetery and are there restrictions on who can be buried there?
- Is the cemetery well maintained and is its maintenance included in the price of a plot?
- How many individuals may use a single plot and are multiple burials permitted, and do the deceased have to be related?
- Can you change your mind and get a refund or even re-sell the plot?

Prepayment Plans

While preparing for the future need for funeral services and products, be very cautious about paying in advance (prepayment plans) especially if you do not know the company with which you are dealing. While most well-established funeral industry entities are trustworthy, there have been many reports of businesses which have mismanaged or stolen funds. Also, when mortuaries or funeral homes go out of business, the moneys you prepaid may be completely lost. You may also find that your moneys are non-refundable if you move to another location and do not need the services of that particular plan or, if for some other reason you want your money back.

Burial at Punchbowl or Other Military or Veterans Cemeteries

If you are a veteran or a spouse or dependent of a veteran who has served in the uniformed services, you may be entitled to have your remains interred in the National Memorial Cemetery of the Pacific, popularly called “Punchbowl” or other military or veteran’ cemeteries in Hawai’i or on the mainland. Space is limited at Punchbowl, especially for burials. Gravesites in Department of Veterans Affairs (VA) national cemeteries cannot be reserved in advance; however, arrangements made prior to 1962 will be honored. Families are encouraged to prepare in advance by discussing cemetery options, collecting the veteran’s military information, including discharge papers, and by contacting the cemetery where burial is desired. Call the US Department of Veterans Affairs (VA) or the Hawai’i State Office of Veterans’ Services for information.

Information about the OVS can be found at <http://hawaii.gov/dod/ovs/> or by calling (808) 433-0420.

The AARP has a free Military Caregiving Guide, which can be found at aarp.org/VetsCareGuide and which addresses specific needs of military families.

Using and Closing Out Bank Accounts

Of immediate financial concern to many who have a joint account or a joint safe deposit box is whether the survivor will have access to the account. Usually, the bank will not freeze your assets if it is in a joint account. Since each financial institution's policies differ, check with them ahead of time. Not only can joint accounts be used prior to and after a death but they can also be easier to "close out" than one that is not jointly held with rights of survivorship. Also recall that joint accounts can be useful tools in estate planning to give survivors immediate access to funds upon death. To close out an account that was in the deceased's name only, you will need a death certificate and, depending on the amount in the account, an affidavit or letters from the court naming you as the personal representative of the estate.

FINDING AN ATTORNEY

Throughout this book, we have suggested that you may need the services of a lawyer. Finding a lawyer can be a very time-consuming and stressful experience, and especially for caregivers who are already stressed. Whether or not you or the person you are caring for is "old," you may wish to consider a lawyer who practices "elder law."

Elder Law

Elder law is the evolving field of law that addresses issues older persons face. Rather than being defined by technical legal distinctions, elder law is defined by the client to be served. In a sense, many attorneys could think of themselves as elder law attorneys, especially when they are preparing estate planning documents, or consulting with a client on a pension plan or retirement timing or Social Security benefits. Elder law is different from traditional estate planning in that more emphasis is placed on planning for longevity and the

contingencies of an extended lifetime. This includes planning for the time when finances, health, mental capacity and support structures may change, either rapidly or progressively.

DEMENTIA-CAPABLE ATTORNEYS

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 older people, including responding to the physical and mental effects of aging on this segment of the population. These professionals should include attorneys who are so-called "dementia-capable," individuals who are trained to recognize the issues of and address problems caused by Alzheimer's Disease and related disorders or dementias (ADRD).

A dementia-capable attorney should be able to (or know someone to partner with who can):

- 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, and other legal matters;
- 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, multiparty 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 Alzheimer's disease related dementias (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 veterans' benefits;
 - Other public, private and governmental benefits, including income, housing, nutrition, home care and personal care services.

Do you know a “dementia-capable” attorney?

How to Locate an Attorney

If you do not have a personal or a family attorney, you may find that a colleague, relative or a friend may have one or know of one who has done a good job. Word of mouth is often a good way to find an attorney. Also a person may call Lawyer Referral Services which are usually run by state and local bar associations such as the Hawai'i State Bar Association which does not charge the public for the referral. Usually, a person who calls a lawyer referral service will obtain the names and telephone numbers of attorneys who subscribe to the service and who have indicated a special interest in certain areas of the law. You can also check through the internet or the "yellow pages" of the telephone book or respond to commercial advertisements. Be cautious and be sure to ask questions about that attorney's experience and costs.

Free Civil Legal Services

The Legal Aid Society of Hawai'i at (808) 536-4302 and Volunteer Legal Services Hawai'i at (808) 528-7046 provide free legal services for eligible clients in Honolulu as well as on the neighbor islands in certain civil cases. The Legal Aid Society of Hawai'i also has a specialized *Kūpuna* Legal Aid Services program at (808) 536-0011 or 1-(888) 536-0011 for neighbor islands.

There are even specialty law offices such as our University of Hawai'i Elder Law Program at (808) 956-6544 for individuals over 60 and caregivers on O'ahu.

Finally, there are other non-profit organizations, such as the Hawai'i Disability Rights Center at (808) 949-2922 and the Domestic Violence Action Center at (808) 531-3771, which utilize attorneys and others to assist clients, including older persons.

Attorney Fees

The first question in entering into a relationship with an attorney may very well be, "How much is this going to cost me?" Always ask if your initial conversation will cost you money. It may surprise you that many attorneys do not offer a "free initial consultation" and you will be expected to pay for your time with the attorney even if it is a preliminary meeting and you decide not to retain the

attorney. Be especially cautious about “non-refundable” deposits, which can be difficult or impossible to get back if you change your mind about the attorney.

Some attorneys may charge a flat fee for certain services. Even under these circumstances, be careful since any additional tasks, changes or modifications may cost you money. Some attorneys charge on an hourly basis. Under this system, time is truly money. Other attorneys may charge on a “contingent fee basis,” a fee arrangement in which the attorney will receive a percentage of what the attorney is able to recover for the client. Not all cases are suitable for payment on a contingent basis and the law prohibits contingent fees for certain kinds of cases, such as criminal cases. Finally, you may wish to “shop around” and get several quotes from different attorneys; but don’t sign with one attorney and then shop.

Working with Your Attorney

When you work with your attorney, be prepared and do your homework. Read this book. Keep your appointments. Show your attorney all of the documents affecting your case, not just selected documents. Make a list of concerns. Remember to bring your written questions with you so you will not forget them and be sure to take notes so that you will remember what your attorney told you. Ask questions. Share your own point of view. Be honest with your attorney. Do not hide facts. Stick to the point when you are talking since, remember, time is money. Make sure you hear and see as well as possible. If you have a hearing aid, wear it. If you have glasses (including reading glasses) bring them and wear them.

NAVIGATING ELDER CARE

For many people, aging in place is the ideal way to grow old, that is, staying in your own home and community with your friends and family close by. It is where you feel comfortable, know your neighbors and like the feeling that you belong there. But aging in place may not be possible. There may come a time when you (or your loved one) might have to go to assisted living or to a nursing home. In the US two out of every three older persons will enter a nursing home sometime during their lives and you or your parent or parents may be the ones. It is highly emotional if you have to move, but it could be even more emotional

for older persons who think that they are still capable of living independently without strangers interfering in their lives.

Moving a person, especially someone who had been strong and independent, from the comfort and familiarity of home into a strange place like assisted living, or a senior living facility, could be highly emotional, especially if the person refuses to go. The older person or care receiver could be scared about aging, making new friends, and fitting in the new place. Perhaps you as a family member or caregiver may be feeling a little guilty also. To help your care receiver feel more comfortable, some suggestions gathered from other caregivers are the following:

- Visit often. Frequent visits can ease any stress care recipients may have. Find out if there is someone in the care home that they might know. They might be afraid that they will be abandoned or they may be lonely. It might be easier for them to meet people at activities or in the dining room if they have a companion. and also be a factor in preventing abuse by the staff or by residents.
- Expect setbacks. Just when you think you are fine and your care receiver is settling in, things will change. Your care receiver might feel lonely or hate the food or the noise or the smells and may want to go home.
- Allow yourself to feel stressed and put upon. Speaking of home, know that when care receivers say they want to go home, it may not necessarily mean to their last address – especially if they have dementia; they may be referring to a childhood home. Home is both a place and a feeling.
- Surround your care receiver with personal belongings; but be sure to tag them. Things get lost or misplaced or even stolen. Moving into an assisted living facility is a major adjustment where everything is different – the people, the food, the routines and even the sounds and smells.
- Be your care receiver's advocate. No place is perfect. Many are hesitant to speak up in a facility, especially at first, and you may be the one who needs to speak up until your care receiver feels more comfortable.

Most of all, no matter how you decide to best navigate elder care, keep yourself safe, healthy and happy. Do visit the UHELP website hawaii.edu/uhelp for more information and for possible changes to the law. Be ready for some setbacks and do not be afraid or embarrassed to ask for and to accept help. Know that you can only do so much. Take care of yourself first for those you care for and for those who care about you so that you can indeed expect the best!



UNIVERSITY OF HAWAII
ELDER LAW PROGRAM
KE KĀNĀWAI MĀMALAHOE



UNIVERSITY *of* HAWAII *at* MĀNOA
WILLIAM S. RICHARDSON
SCHOOL OF LAW

This publication was funded through a grant from the Hawai'i Justice Foundation and support from the William S. Richardson School of Law at the University of Hawai'i.