

**DOCUMENTING LONG-TERM CARE, INCAPACITY, AND
END-OF-LIFE DECISIONS¹**

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- I. Long-Term Care Options and Planning in a Nutshell³
- A. Federal Programs and Public Housing: Federal government programs exist that provide both rental and mortgage assistance to the elderly.⁴ Some of the most-widely used programs include:
1. Section 202 Supportive Housing for the Elderly is a Housing and Urban Development (“HUD”)-administered program that provides supportive housing for very low-income persons age 62 and older. This program gives capital advances to non-profit organizations to construct or rehabilitate structures that will serve as supportive housing. Support services include activities such as cleaning, cooking, and transportation. Capital advances do not need to be repaid so long as supportive housing remains available for at least forty years. This program also includes funding to cover the difference between what the renter can pay and the cost of operating the project. To be eligible for residency in Section 202 housing, one occupant must be 62 years or older with a household income at or below 50% of the area median income.
 2. Section 8 Housing Choice Voucher Program is a federally funded program that distributes vouchers through state, regional, and local housing agencies. Section 8 assists both renters and homeowners

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² I would like to thank my Legal Assistant, Kristie Ehlers, for her assistance in preparing these materials.

³ See Appendix A for a listing of Area Agencies on Aging in Maryland and Senior Information and Assistance Coordinators in Maryland who can help seniors with their long-term care plans.

⁴ Some helpful government websites that describe federal housing programs and mortgage assistance include: aging.md.gov/housing, mdhomeprograms.com, and portal.hud.gov/hudportal/HUD?src=/topics/information_for_senior_citizens.

whose income does not exceed 50% of the area median income. For rental units, the public housing agencies pay the rental subsidies directly to the landlords and the tenants pay the remaining difference. For homeowners, this program provides families with the opportunity to purchase their first home and helps with related expenses.

3. Public Housing is a federal program that provides rental housing to low-income families, elderly, and disabled individuals. The federal government provides financial aid to local public housing agencies that manage housing for lower income residents. Rent is based on the highest of the following: (a) 30% of the resident's monthly adjusted income, (b) 10% of the resident's monthly gross income, (c) the resident's welfare shelter allowance, or (d) a minimum rent established by the public housing agency. Typically there are very long waiting periods for public housing.
4. Home Equity Conversion Mortgage Program⁵ ("HECM") is the Federal Housing Administration's ("FHA") reverse mortgage program that enables seniors to withdraw some of the equity in their homes. Program participants may elect to receive funds in a fixed monthly amount, a lump sum, a line of credit, or some combination of these options. This program may also be utilized to purchase a new primary residence if there is cash on hand (typically from the sale of a property). No repayment is due until the borrower no longer uses the property as his primary residence. To be eligible, a person must be 62 years of age or older, have equity in the property, occupy the property as a principal residence, not be delinquent in any federal debt, and participate in a consumer counseling session. Not all reverse mortgage programs are FHA-approved.
5. Home Affordable Modification Program⁶ ("HAMP") is a federal program intended to help struggling homeowners avoid foreclosure. To be eligible, the residence must be owner-occupied,

⁵ Information about this program can be found at portal.hud.gov/hudportal/HUD?src=/program_offices/housing/sfh/hecm/hecmhome.

⁶ Information about this program can be found at makinghomeaffordable.gov/programs/lower-payments/Pages/hamp.aspx.

have a mortgage balance of less than \$729,750, and the owners must owe monthly payments that exceed 31% of their income and demonstrate financial hardship.

- B. Housing Options for Seniors:⁷ Housing options for the elderly will depend upon an individual's physical and medical needs, social and emotional needs, and financial needs.
1. Aging in Place:⁸ Many seniors wish to stay in their homes as long as they are able to do so. This option is most suitable for seniors who have a nearby network of friends and family, utilize a neighborhood senior center⁹ or other public or private community resources, and/or easy access to transportation. Private geriatric care managers¹⁰ can provide guidance to individuals who wish to age in place.

Even seniors who require some assistance with activities of daily living may be able to remain in their homes by utilizing privately or publicly funded day care or in-home help. Maryland offers a limited number of waivers to individuals to enable them to receive home and community-based services as an alternative to institutional care. Some examples of such waivers include the Older Adults Waiver, Living at Home Waiver, and Medical Day Care Waiver.¹¹

⁷ Some helpful websites for senior housing resources include: seniorliving.org, helpguide.org/elder/senior_housing_residential_care_types.htm, seniorhomes.com, and mhcc.maryland.gov/consumerinfo/longtermcare/AlternateLiving.aspx.

⁸ Some helpful websites for seniors living at home include: aginginplace.org, aging.maryland.gov/seniorcenterslist.html, and mhcc.maryland.gov/consumerinfo/longtermcare/LivingAtHome.aspx.

⁹ A listing of senior centers in Maryland can be found at aging.maryland.gov/seniorcenterslist.html.

¹⁰ A geriatric care manager is a trained professional specializing in assisting older people and their families with long-term care arrangements. To find one, visit the Mid-Atlantic Geriatric Care Manager website at www.midatlanticgcm.org.

¹¹ One website that describes Maryland waiver programs is mmcp.dhmh.maryland.gov/waiverprograms/SitePages/Home.aspx.

Safety is an important consideration for an aging individual who wishes to continue to reside at home.¹² It is often necessary or advisable to make modifications to a home as its occupant ages, such as replacing steps with ramps or lifts, installing grab bars and handrails, removing area rugs, lowering storage shelves in closets, kitchens, and bathrooms, installing easy-open doorknobs and light switches, and adding automatic shut-off systems for kitchen appliances.¹³ It is also likely that the occupant will need assistance with tasks such as yard work, cleaning, shoveling, and minor home maintenance and repairs. A senior who lives alone (and his loved ones) may gain peace of mind by utilizing a personal emergency response service¹⁴ that will communicate with the senior and alert the appropriate personnel in the event of a health emergency, home intrusion, fire, or carbon monoxide poisoning.

2. Senior Living Communities: Senior living communities, sometimes referred to as 55+ communities, are suitable for individuals age 55 and over who are able to live on their own. Most senior living communities offer amenities like clubhouses with activities, yard maintenance, housekeeping, and transportation. These communities can be comprised of houses, townhomes, condominiums, or apartments.
3. Assisted Living Facilities: Assisted living facilities are communities for seniors who want an independent lifestyle, but need some assistance with their activities of daily living. These communities vary significantly in terms of setting, services, and cost. Assisted living providers typically provide assistance to residents with dressing, bathing, eating, and managing medications. Assisted living facilities in Maryland are regulated by the Office of Health Care Quality at the Department of Health and Mental Hygiene. Prior to entering into an assisted living facility, prospective residents (and possibly family members or trusted advisors) should

¹² A Housing Safety Checklist for Older People is attached in Appendix B.

¹³ CHAI's Home Repair Program for Seniors and People with Disabilities (chaibaltimore.org) assists qualifying individuals in Northwest Baltimore with home safety modifications and provides general handyman services.

¹⁴ One company that provides personal emergency response services is Life Alert (lifealert.com).

review the Residential Agreement, list of services offered, notice of resident's rights, list of costs, disclosure statement, and any other documents that residents are required to sign.¹⁵ It is also important to contact the local Long-Term Care Ombudsman to see whether the provider has received complaints.¹⁶

4. Nursing Homes: Nursing homes¹⁷ are appropriate for individuals who require 24-hour nursing care or assistance, but do not need to be in a hospital. Residents may stay in a nursing home long-term or on a temporary basis for nursing care and rehabilitation after a hospital stay before going home. Some nursing homes are set up like hospitals and offer a broad range of care options such as physical therapy or occupational therapy. Certain facilities have special units for Alzheimer and dementia patients. The Centers for Medicare and Medicaid Services ("CMS") establishes standards for the operation of nursing homes that receive funding from Medicare or Medicaid. The Maryland Office of Health Care Quality also regulates nursing homes and the local Long-Term Care Ombudsman helps to protect their residents.

6. Continuing Care Retirement Communities ("CCRCs"): CCRCs¹⁸ combine independent living, assisted living, and nursing home care in one facility to accommodate residents' changing needs. CCRCs are attractive to seniors who want to live in one location for the rest of their lives. This is the most expensive long-term care option and is suitable only for those seniors with substantial financial means. Typically CCRCs require substantial entry fees as well as monthly charges. The three main types of CCRC contracts are:

¹⁵ Page 14, Assisted Living in Maryland – What You Need to Know, which can be found at aging.maryland.gov/documents/ALGuide_002.pdf.

¹⁶ The website for the Maryland Long-Term Care Ombudsman is aging.maryland.gov/Ombudsman.html.

¹⁷ The Maryland Health Care Commission offers an online tool to search for a nursing home at mhcc.maryland.gov/consumerinfo/longtermcare/SearchPage.aspx?qs=NH.

¹⁸ A listing of CCRCs in Maryland can be found at The Maryland Health Care Commission offers an online tool to search for a nursing home at aging.maryland.gov/retirementcommunities.html.

- a. Extensive or Life Contracts – these are the most expensive because they provide unlimited assistance and health services with no extra costs;
- b. Modified Contracts – these offer limited health services as part of the initial monthly fee, and additional health services are provided for an additional fee; and
- c. Fee-for-Service Contracts – these offer a low initial enrollment fee, and assisted living or skilled nursing services will be provided as needed for additional fees.¹⁹

The average CCRC entrance fee in 2010 was \$248,000.²⁰ Entrance fees may be partially or fully refundable upon termination or death. CCRCs are required to disclose their financial information to prospective and existing residents. This information should be carefully reviewed before agreeing to move to a CCRC.

- C. Paying for Long-Term Care: Long-term care can be quite costly, so it is critical to plan ahead. For example, in Maryland in 2012, a private room in an assisted living facility costs an average of \$38,400, a home health aide costs an average of \$45,760, and a private room in a nursing home costs \$95,995.²¹ Seventy percent of adults will require long-term care services after age 65.²² There are many options for funding long-term care, including purchasing long-term care insurance²³, obtaining a reverse mortgage, utilizing trust, investment, or annuity income, depending on family financing, or Medicaid²⁴.

¹⁹ Continuing Care Retirement Communities: What They are and How They Work published on the AARP website at aarp.org/relationships/caregiving-resource-center/info-09-2010/ho_continuing_care_retirement_communities.html.

²⁰ Page 9, Today's Continuing Care Retirement Community published in July 2010 and available at http://www.leadingage.org/uploadedFiles/Content/Consumers/Paying_for_Aging_Services/CCRCcharacteristics_7_2011.pdf.

²¹ From the Genworth Financial Report entitled "Maryland – State Median: Annual Care Costs in 2012" that is set forth in full in Appendix C.

²² From the National Clearinghouse for Long Term Care Information website located at longtermcare.gov.

²³ The Maryland Insurance Administration maintains a list of insurance companies that are approved to sell individual long-term care policies in Maryland that can be found at www.mdinsurance.state.md.us.

²⁴ In order to participate in Medicaid, federal law requires states to cover certain population groups (mandatory eligibility groups) and gives them the flexibility

II. Advance Medical Directives

- A. Maryland Statutory Advance Directive:²⁵ The Maryland Health Decisions Act authorizes adults to make their own decisions regarding their medical treatment. The State offers a form to assist with this planning,²⁶ but there is no requirement to use this specific form.²⁷ This form enables individuals to name a health care agent to make decisions in the future if the individual becomes unable to do so, to state their treatment preferences at the end of their lives, and to describe their wishes for their bodies and related arrangements after their deaths. Some practitioners prefer to use separate documents for the Living Will and Power of Attorney for Health Care rather than combining them into an Advance Directive. These documents are valid in Maryland even if they were prepared and signed in another state, so long as they were valid in the state in which they were prepared.
- B. Living Will: A living will is a document which enables an individual (the “Declarant”) to presently make decisions about life-sustaining procedures if, in the future, he is in a persistently vegetative state or his death from a terminal condition or end-stage condition becomes imminent.
1. Requirements: A living will must be prepared by a competent adult and signed in the presence of two witnesses. At least one of the witnesses must be a person who will not knowingly benefit financially by reason of the death of the Declarant.
 2. Effective date: Before a living will can be used to guide medical decisions affecting the Declarant, two physicians must certify that the Declarant is unable to make medical decisions and that he is either in a persistent vegetative state or terminally ill.
 3. Enforceability: The Supreme Court has recognized the right to control one’s medical treatment, including the right to die with

to cover other population groups (optional eligibility groups). States set individual eligibility criteria within federal minimum standards.

²⁵ The Maryland Office of the Attorney General has prepared a Guide to Maryland Law on Health Care Decisions that can be found at oag.state.md.us/Healthpol/adirective.pdf.

²⁶ A copy of this form is provided in Appendix D.

²⁷ Another popular form is called “Five Wishes” and is available from the non-profit organization, Aging With Dignity (agingwithdignity.org).

dignity.²⁸ A medical professional is obligated to follow “clear and convincing evidence” of a patient’s wishes, even if those wishes conflict with the desires of relatives, hospital policies, or principles of those providing medical care.

4. Flexibility: Some individuals feel more comfortable having their end-of-life decisions applied with flexibility by their health care agents rather than stating that their wishes are final.
5. Absence of a Living Will: If a health care provider is unaware of the existence of a living will or designation of a surrogate decision maker (or if the designation fails for any reason), and a patient becomes incapable of making an informed decision about his health care, Maryland’s surrogate decision making statute²⁹ controls who may make decisions on the patient’s behalf and how to handle disputes among decision makers. The statute establishes an order of priority, and individuals or groups in a particular class may be consulted to make a decision only if all individuals in the next higher class are unavailable. If surrogates with equal decision-making priority disagree about a health care decision, the health care provider may refer the case to the institution’s patient care advisory committee for a decision. If the patient is not in a hospital or related institution, a physician may not withhold or withdraw life-sustaining procedures if there is not agreement among all of the surrogates in the same class.

C. Power of Attorney for Health Care: This document allows a person (the “Principal”) to designate someone else (the “Health Care Agent”) to make health care decisions on his behalf.

1. Requirements: A Power of Attorney for Health Care must be prepared by a competent adult and signed in the presence of two witnesses. At least one of the witnesses must be a person who will not knowingly benefit financially by reason of the death of the Principal. The designated Health Care Agent may not serve as a witness. The Health Care Agent may be any adult except an owner, operator, or employee of a health care facility from which

²⁸ The first Supreme Court case recognizing the right to die was *Cruzan v. Missouri Department of Health* (1990).

²⁹ Annotated Code of Maryland, Health - General Article Section 5-605, is set forth in Appendix E.

the Principal is receiving care, or any immediate family member of a person that is disqualified.

2. Authority of a Health Care Agent: The authority of a Health Care Agent is subject to the conditions imposed by the Principal, but generally includes the power to: request, receive, and review any information regarding the Principal's physical or mental health and consent to disclosure of this information; employ and discharge health care providers; authorize admission to or discharge from any hospital, hospice, nursing home, adult home, or other medical care facility; and consent to the provision, withholding, and withdrawal of health care, including, in appropriate circumstances, life-sustaining procedures.
3. Effective date: A Power of Attorney for Health Care typically becomes effective when the Principal's attending physician and a second physician certify in writing that the patient is incapable of making an informed decision.
4. No written or oral designation of a Health Care Agent: As with Living Wills, Maryland's surrogate decision-making statute controls if a patient becomes incapable of making an informed decision about his health care and the physician is unaware of the existence of a document designating a Health Care Agent. See Section B(5) above for additional information about the surrogate decision-making statute. It may become necessary for the circuit court in the county in which the Principal resides to appoint a guardian if no one listed in the surrogate decision maker statute is willing or able to serve in that capacity.

III. Power of Attorney for Property: This document allows a person (the "Principal") to designate someone he trusts to manage his financial affairs if he becomes incapacitated. The Principal is able to direct whether the Power of Attorney for Property shall become effective immediately or effective only upon proof of incapacity of the Principal. The Principal is also able to limit or expand his Agent's authority as he deems appropriate.³⁰

³⁰ Certain duties of the Agent may not be modified by the Principal, including the duty to act with care, competence and diligence in accordance with the Principal's expectations and best interest and acting within the scope of authority granted by the Principal.

- A. Maryland General and Limited Power of Attorney Act (Title 17 of the Estates and Trusts Article of the Maryland Code): This Act was created for the dual purposes of facilitating acceptance of powers of attorney by financial institutions and increasing accountability of Agents. This Act went into effect on October 1, 2010, and substantially changed the way that powers of attorney are drafted and enforced. Some of the major changes include:
- providing two statutory forms³¹ that may be used by the Principal, where none had previously existed;
 - establishing that if a person or entity refuses to honor a power of attorney substantially similar to either statutory form, the Agent may obtain a court order mandating acceptance of the statutory power of attorney and imposing liability for reasonable attorney's fees and costs incurred in bringing such action;
 - stipulating that a person or entity cannot require a Principal to execute an additional or different form of power of attorney for any authority granted in a statutory power of attorney;
 - directing that a power of attorney shall remain enforceable until the Principal dies regardless of how much time has elapsed if no other terminating event has occurred; and
 - mandating that powers of attorney executed on or after October 1, 2010, must be in writing, signed by the principal (with certain exceptions), attested and signed by two or more adult witnesses, and notarized.
- B. Impact on practitioners: Since the Maryland General and Limited Power of Attorney Act was implemented, practitioners have debated the best way to achieve their clients' goals. One issue that has raised much discussion is what qualifies as a "statutory form power of attorney." Section 17-101(g) of the Estates and Trusts Article of the Maryland Code defines this term as "a power of attorney that is substantially in the same form as one of the powers of attorney set forth in Subtitle 2 of this title." A power of attorney will not be considered to be a statutory form power of attorney if it incorporates

³¹ One statutory form is the Personal Financial Power of Attorney, which is attached in Appendix F. The other statutory form is the Limited Power of Attorney, which is a 17-page "check the box" style form that is available at msba.org/sec_comm/sections/estate. Please note that these forms were recently updated by legislation effective October 1, 2012.

by reference one or more provisions of another document into the “Special Instructions” section of a statutory form power of attorney.³²

It remains unclear how much a practitioner can tailor the form to achieve a client’s goals before it will be considered not to be in substantially the same form as the statutory power of attorney. Some practitioners have opted to use one of the statutory form powers of attorney, some have opted to continue to use their own forms that they have created, and some use a statutory form and a supplemental form power of attorney. If using a supplemental form along with a statutory form, one must be careful not to incorporate such document by reference in the “Special Instructions” section of the statutory form.

It seems that many more practitioners are using the Personal Financial Power of Attorney than the Limited Power of Attorney because the length of the document and the numerous decisions that Principal must make may be overwhelming. It is important to note, however, that the Personal Financial Power of Attorney omits several important areas such as gifting powers that practitioners commonly recommend for clients in their powers of attorney.

- C. Curbing Power of Attorney Abuse: The Maryland General and Limited Power of Attorney Act helps to curb abuse by, among other things, giving more parties standing to demand a financial accounting or petition the circuit court to review the actions of the Agent.³³ In the event that financial abuse is suspected, the Principal or other interested party should contact the Maryland Department of Human Resources at 1-800-917-7383. The Department will contact Adult Protective Services in the appropriate county to investigate.

IV. Do Not Resuscitate Orders and Organ Donation Considerations

- A. The Maryland Health Care Decisions Act was amended on October 1, 2011, to include Medical Orders for Life Sustaining Treatment

³² Section 17-101(g) of the Estates and Trusts Article of the Maryland Code.

³³ The author has recently filed a Petition in the Circuit Court for Harford County, Maryland, on behalf of an adult child of the Principal to Order the Production of Documents, Construe the Power of Attorney, and Review the Agent’s Conduct. This action is one of first impression in Harford County.

("MOLST").³⁴ The purpose of this legislation is for the Maryland Department of Health and Mental Hygiene to develop a form that health care facilities will be required to use across various health care settings in order to insure that an individual's wishes regarding life-sustaining procedures will be honored. The goal is for a patient's form to become part of his medical record that will follow him throughout his care.

A draft form is currently available on the website marylandmost.org and is provided in Appendix H. As of October 1, 2012, health care facilities may implement the MOLST forms and processes, but are not yet required to do so.³⁵ The MOLST form includes "do not resuscitate" provisions in addition to options in situations other than cardiac arrest such as artificial ventilation, blood transfusions, and dialysis. It is intended to replace the current EMS DNR form,³⁶ but such form remains available and enforceable. The MOLST form is a medical document that must be completed with a medical service provider. It does not replace an advance directive.

B. Organ Donation Considerations

1. How to Become an Organ Donor: The organ donor program in Maryland is managed by the Living Legacy Foundation of Maryland. An individual may register as an organ donor online at donatelifemaryland.org or through the Maryland Motor Vehicle Administration ("MVA"). The MVA processes organ donation requests at the time of applying for or renewing a Driver Services product or upon receipt of an organ donor form.³⁷ An individual is not required to register as an organ donor, and can indicate his wishes in a living will or last will and testament.

³⁴ This is codified in Section 5-608.1 of the Health – General Article of the Annotated Code of Maryland, which is set forth in Appendix G.

³⁵ See the FAQ sheet disseminated by the Department of Health and Mental Hygiene on September 30, 2011, and attached as Appendix I regarding the delayed implementation of MOLST.

³⁶ This form is available at miemss.org/home/portals/0/docs/otherpdfs/dnrorder_form.pdf and is provided in Appendix J.

³⁷ The MVA organ donor form is available at mva.maryland.gov/Resources/DL-087.pdf and is provided in Appendix K.

2. Whole Body Donation: An individual may elect to donate his body for use at medical schools for training and research. This election may be made through the State Anatomy Board (dhmh.maryland.gov/anatomy/sitepages/faqs.aspx), the Anatomy Gifts Registry (anatomicgift.com), or the International Institute for the Advancement of Medicine (iiam.org). Until recently, another option has been to donate one's body for plastination,³⁸ which is a method of halting decomposition and preserving anatomical specimens for science and medical education. However, the Institution for Plastination in Heidelberg, Germany, has indicated on the bodyworlds.com website that it has reached its capacity and is unable to accept new registrations at this time.
3. Alternatives to Registration for Organ or Whole Body Donation: An individual is not required to register as an organ or whole body donor, and can indicate his wishes in a living will or last will and testament. In the absence of registration or other instructions, such decision shall be made in accordance with Section 5-509(c) of the Health – General Article of the Annotated Code of Maryland. This section establishes the following order of priority: (1) surviving spouse or domestic partner of decedent; (2) adult child of decedent; (3) parent of decedent; (4) adult sibling of decedent, (5) person acting as representative of the decedent under a signed authorization of the decedent; (6) guardian of the person of the decedent if one has been appointed; (7) any other person willing to assume the responsibility to act as the authorizing agent after attesting in writing that a good faith effort has been made to no avail to contact any of the individuals with higher priority.
4. Tips for Practitioners: It is helpful to include organ donation instructions in both the client's will and living will. Clients who wish to be donors should specify whether they wish to donate all needed organs, tissues, or eyes or only specific organs, tissues, or eyes. Such clients should also specify whether donated organs, tissues, or eyes shall be used for transplantation, medical research, or any other purpose authorized by law.

³⁸ This process was invented by scientist and anatomist Dr. Gunther von Hagens in 1977. His work has been displayed throughout the world on exhibit entitled "BODY WORLDS."