

## Decline, Approaching Death, and Dying: *Ways to Meet Challenges*

### Contents:

- Spiritual aspects: queries, Langley Hill resources, other resources
  - Care for Body and Mind: advance directive provisions, practical care arrangements (including senior-friendly residence, in home care, assisted living, skilled nursing home, hospice services, continuing care communities, Medicaid), related resources, communications, dying, related resources
  - Care for Property: general powers of attorney, lawyer referral services
- Related forms in pocket:*** VA, MD and DC general powers of attorney

This, the second of three documents in Langley Hill Friends Meeting's packet on decline and death, provides advice and resources on the spiritual, physical, mental and property challenges that arise during a person's growing incapacity to manage his or her own life, and during the approach to death and the dying process. The document is aimed at helping those who are anticipating or coping with an incapacitating decline, or are helping someone in decline.

As with the other documents, this one is arranged with spiritual issues considered first, practical aspects of the body and mind second, and property-related issues third. Although the challenges faced during a decline leading toward death are similar to those faced with a major disability at any age that limits a person's ability to take care for one's self, this document focuses on the gradual loss of physical or mental capacities, that often precedes death. Unlike the first and third documents, this one might not be relevant for many of us.

### 1. **Spiritual aspects of Decline:**

#### a. **Queries To Help about Your Loved One's Decline and Death**

§ How can I recognize that someone is increasingly dependent on me for help with basic daily self-care tasks, like getting dressed, bathing, toileting, remembering routines and important timing for things like a dish on a hot stove? If I am not in a position to be with that person, do mishaps take place often enough to raise questions that the person may need expert help? To whom can I turn for advice on how best to help this person?

§ If I am the primary caregiver for someone in decline, how can I muster others' support for his or her needs as well as my own? Can I call on friends or other caregivers to give me an occasional respite? What other kinds of paid or volunteer help do we need?

## 2 Decline and Approaching Death: *Ways to Meet Challenges*, 2014 version

§ How can I arrange my life to give myself timely opportunities to work through my grief? How do I accept that others may need a different amount of time, or different conditions to work through their grief? How can I get others to understand my grieving needs, and how can I learn to understand theirs?

§ How can I help a dying person who denies any negative feelings about weakness or his own impending losses to come to terms with the inevitability and closeness of his or her death?

§ Anyone who depends emotionally on someone who has become incapacitated or is approaching death will grieve. Grief can take months or years to subside, and it may last longer if suppressed. Can I allow myself to vent my grief? How, and with whom? Whom shall I call upon to help me to survive and emerge from the depressing times ahead? How can I help others who are going through this same process with me? Is professional counseling needed?

§ Is my support for someone who grieves confined to conventional comforting? How can I persist in my support for someone who is grieving for an extended period of time, or whose grief returns? How can I communicate a real willingness to be available for help? How can I best be supportive if I feel I can't or won't take on much of the responsibility to help another work through grief? How can I communicate that support?

§ How can I make asking for help more comfortable, after others appear to have resumed their normal lives?

### **b. Resources: *Meeting and other***

#### **i. Langley Hill Resources:**

If requested, the Clerk of the Committee for Care and Clearness will appoint a clearness or support committee to meet with family members faced with difficult questions, such as terminal illness, lasting coma, serious brain damage, chronic pain, grief, or the logistical, practical and emotional problems of life without the person who is in a decline or approaching death.

If the next of kin are stretched thin financially by the expenses of illness or of the burial or funeral expenses, or otherwise because of the death, they might approach the Care and Clearness committee for help from the Family Emergency Fund.

#### **ii. Other spiritual resources:**

**(Also see *grieving resources in the document on Death: Help for Survivors.*)**

\*Smith, Bradford, 1965, *Dear Gift of Life: A Man's Encounter With Death*, Wallingford, PA: Pendle Hill Pamphlet No. 142, 38 pp. *As the author faces his final months with cancer, he shares rich meditations on the meaning and wonder of life; the intensity of life in finite time. "If we cannot speak freely of death, we cannot really speak freely of life."*

Callahan, M., & Kelley, P. 1992. *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*. New York, Simon & Schuster.

<http://www.wikihow.com/Prepare-for-the-Death-of-a-Loved-One> . This Wiki is an accumulation of advice about the steps that help to ease the impact of an impending death.

**National Caregivers Library**, a website of a for-profit Family Care America, Inc., provides an abundance of materials, books, advice and advertising for those who must care for another. <http://www.caregiverslibrary.org/home.aspx> .

\*Ostrow, W. 2006. **In God We Die** Pendle Hill Pamphlet 385. 36 pp.

\*Taylor, P. [1981] 1989. **A Quaker Look at Living with Death and Dying**. Philadelphia Yearly Meeting. 32pp. *Papers from PYM Death and Dying Conference in 1981*.

Yungblut, J., 1990. On Hallowing One's Diminishments. Wallingford, PA, Pendle Hill, Pamphlet #292.

Becket, Marilyn R., 1992, **Last Touch: Preparing for a Parent's Death**, Oakland, CA: New Harbinger Publications, 143 pp. *A short set of intimate stories about how one family coped with their aging father's passing away.*

Jim Bond, a member of Langley Hill, was facing his final days when he wrote this poem in 1998:

*Let go, he said, and fall  
Into the everlasting arms;  
Your frantic grasp upon the edge  
Of sullen life is useless now.  
Unhand the day, and unheeding fall  
Into Eternal care.*

*But no, I plead;  
I sense no sure embrace.  
I fear an everlasting fall  
Into a cruel and empty space.*

*Remember yet, he said,  
The gentle curvature of space,  
Encircling time and you;  
Hold, in its arms  
The wholeness of us all,  
And tenderly, returns your fall.  
Let go, he said, and rise  
Into the endless skies.*

2. **Body and Mind aspects of Decline:**
  - a. **Advance Directive Provisions**

An Advance Directive, as described more fully in the accompanying document on planning for decline and death, provides for the appointment of an agent to act on behalf of the signer if he or she becomes incapacitated. The agent then can make decisions relating to the care of the individual, based on the best interests of the person as the agent sees them. It is worthwhile for anyone appointed in an Advance Directive as an agent to consult all of those most interested in the person's welfare when called on to make significant decisions under the Advance Directive.

In the absence of an advance directive, informal care arrangements can work either until decisions have to be made about care arrangements with the knowing consent of the individual being cared for, and that person cannot or will not do so, or until the person must be moved to a situation, such as a hospital or nursing home, in which a "next of kin" or other primary caregiver must be designated for assistance with care decisions, payments, etc. Very often in these situations legal arrangements must be made quickly, and at considerable expense.

**b. Practical care arrangements:**

Anyone facing decline or approaching death will need to consider the available options for life support during that period:

***Moving to a More Senior-Friendly Residence:*** As we age we become increasingly less able to manage stairways, loose rugs and other floor irregularities that cause falls, driving a vehicle, remembering things such as a stove burner left on or a door unlocked, walking long distances, and a variety of other daily challenges that we had navigated easily until recently. We also find ourselves newly feeling burdened with the daily chores of managing a home, cooking our meals, and doing routine repairs, maintenance, and gardening. A common response to this is to move to simpler, smaller quarters such as an apartment near public transportation, hospitals, etc. Such a move can provide a degree of freedom and confidence that one can continue to be relatively self-sufficient for much of the rest of one's life. At the same time it disrupts the continuity of familiar quarters and neighbors, and requires the establishment of new routines and friendships. The disposal of most of a lifetime's accumulation of possessions can be burdensome and very time consuming. As with planning generally, it is best to make such a move well before the challenges become insurmountable.

***In Home Care:*** For any decline there are several kinds of care that involve varying demands on the principal caregiver (usually a loved one). According to the Center for Disease Control (CDC), [90% of Americans](#) who need long term care get it from unpaid family members. That puts a strain on a lot of relatives who have neither enough time nor the training to care for loved ones.

Home care, with the caregiver in residence and the person with a disability living as close to his or her accustomed way of life as the disability permits, is the simplest and least expensive option. But the demands of helping the disabled person may be more time-consuming or more specialized than the caregiver is able or willing to provide, so home care services can be obtained from individuals or agencies in the locality. (See references below for local resource and referral agencies). These services can range from medical alert lanyards, worn constantly to allow immediate notice to emergency services in case of a fall or other emergency, to constant attendance by trained nurses. Medicare pays only for home care for 60 days for each episode in which it is needed for health conditions that make unassisted transportation from the home difficult.

*Related Resource:*

Montgomery County Government, **Information & Assistance for Seniors**, (240) 777-3000, *provides free advice to Montgomery County residents about finding and selecting home care and support services.*

Montgomery County Government, **Telephone Reassurance Program** for Caregivers over 60, 240-777-2600, *offers informal advice and support for older caregivers.*

From <http://blog.virginiaelderlaw.com/2014/03/and-the-oscar-for-best-alzheimers-patient-goes-to/>: These are some available caregiver training options:

- The Alzheimer's Association has several free, online [tools](#) to help caregivers find answers, local resources and support.
- The National Parkinson's Foundation has a list of [caregiver resources](#) and a free manual called [Caring and Coping](#).
- AARP has several [free on-line seminars](#) on family caregiving topics such as housing options, the basics of handling caregiving, providing the care, and planning for the care of aging parents.
- AARP has also prepared comprehensive materials for caregivers called "[Next Step in Care](#)." Although the focus isn't on nursing-style caregiving tasks, three might be useful: a [self-assessment tool](#) for family caregivers, a [medication management guide](#), and a [guide to hospice and palliative care](#).
- Many home health-care companies, such as [Five Star Home Health Care](#) in Fairfax, offer a 40-hour Caregiver class, where you can learn personal care assistance; home management; safety and accident prevention; infection control; and food, nutrition, meal preparation and how to help a loved one with activities of daily living such as bathing and toileting.
- The American Red Cross offers a [training manual](#) for caregivers that has a DVD explaining the mechanics of transferring another person from bed to chair and back, and a few other complicated tasks.
- Also, some videos are available for free at [www.mmlearn.org](http://www.mmlearn.org), a Web site that says its mission is to provide caregivers with online training and education.

*In addition, the best way for caregivers to learn caregiving techniques is to ask a professional for help. If your loved one is in the hospital, make sure care instructions are clearly explained to you before discharge. If you don't get them to your satisfaction, don't sign the form that says you have been given instructions on what to do. The*

*hospital is legally obligated to ensure that discharges are safe, and this operates in a caregiver's favor. The same goes for the pharmacy: don't sign that sheet that the pharmacist hands you indicating that you have been adequately informed about the medications you are purchasing if you haven't been.*

**Assisted Living:** The next step up the ladder of services, expenses, and disruptions, is assisted living, in a building with others needing this same kind of help. Attendants provide basic assistance that the disabled person requires, such as washing, toileting, dressing, eating, etc. Expert nursing services usually are not part of this arrangement, although limited services of a nurse, such as the administration of medications, is provided. Usually the spouse of someone in assisted living is not allowed to cohabit there without paying for an unnecessary level of services.

**Skilled Nursing Home:** A third step of intensity is a nursing home, where the assistance is more intensive, accompanied by expert nursing services, various forms of therapy, and monitored attendance. A variant of these services is provided for those suffering memory losses and other symptoms of dementia, with reduced physical care and more dementia-related therapy. Medicare rates these facilities according to their compliance with regulations, staffing, quality measures, and overall. You can make closer comparisons by entering your residence location at <http://www.medicare.gov/quality-care-finder/#nursing-home-compare>. The care can be quite expensive, and Medicare only pays for 90 days of assisted living or nursing home care, apart from hospice care.

**Hospice Services:** All of these forms of professional care can be provided as hospice services for those whose conditions have been diagnosed as terminal, with a life expectancy of less than six months in their normal course. The services can be extended for repeated six-month periods with a similar certification. Hospice services are provided on the condition that the patient will not request or require treatments designed to reverse or cure the life-threatening condition. Medicare pays for most hospice services for those with Medicare Part A benefits, including palliative care to reduce the pain and inconvenience from the terminal condition and its medications, without unusual efforts to prolong the patient's life.

*Related Resource:*

**The National Hospice and Palliative Care Organization** has a "search" function with which you can find a list of local hospice and palliative care organizations. <https://netforum.nhpco.org/eWeb/DynamicPage.aspx?Site=NHPCO&WebKey=a9338cdd-546a-42f5-9061-6b91dbdb31da>.

**Hospice Net**, 401 Bowling Avenue Suite 51 Nashville, TN 37205-5124, is a nonprofit resource for those contemplating hospice care for themselves or another, with a variety of materials and advice at [www.hospicenet.org](http://www.hospicenet.org).

**Hospice Link**, (800) 331-1620, provides resources and referrals to hospices.

[www.americanhospice.org](http://www.americanhospice.org) offers advice and links about hospice care.

<http://www.caringinfo.org>, the website of the National Hospice and Palliative Care Association, based in Alexandria, provides medical advance directive forms tailored for local jurisdictions and kept current with legal developments.

**Continuing Care Communities:** Often all four of the above forms of care are provided in continuing care communities, which provide for independent living for seniors as well as these other forms. The Medicare Nursing Home rating system referred to above includes continuing care communities, and can be helpful in making these choices.

*Related Resource:*

**Leading Age**, <http://www.leadingage.org>, is an organization of those who work “to expand the world of possibilities for those who are aging”. Its website has a search function to find continuing care communities, etc. **Friends Services for the Aging**, <http://www.fsainfo.org>, is the Quaker equivalent of Leading Age for Friends-related aging services.

**Medicaid:** Medicaid will pay for the expenses of any of these forms of care for patients who meet the State requirements to qualify for Medicaid coverage. These requirements often include complex, changing limits on the annual income and the net assets of the Medicaid applicant. A *Maryland* resident must be at least 65, or disabled, or blind, or under 21, or caring for a related child in the home, or pregnant, or parents of an unmarried child under 21, as well as meeting income and net asset limits based on the number of people in the family. In *Virginia*, residents are eligible if they are children under 10, pregnant women, Supplementary Security Income recipients, aged 65 or older, blind or disabled, needing long-term care, covered by Medicare, covered by Plan First Services, or in the Breast & Cervical Cancer Early Detection Program, and meeting a complex formula for family income limits. For the District of Columbia, residents must be pregnant, parent of a dependent child under 19, blind, disabled or living with a disabled family member, or at least 65 years old, as well as meeting family income limits (based on the Federal Poverty Level). For all these jurisdictions, consult the references below for further details.

**c. Communications:**

Almost everyone has supportive relationships with other people, and these matter on both sides. When someone becomes incapacitated or is approaching death, family and friends need to know that and usually want to be supportive. This support can be very concrete, such as providing food for the family or substitute care for the incapacitated person so that the normal caregiver can have a respite. Perhaps even more significantly, supportive friends can provide spiritual and other compassionate support to the dying person and the caregiver. Both the person on the receiving end and the giver

benefit from this support, often making the decline or final days a much lighter burden to carry on either side.

In a few lucky cases, the indisposed person will have prepared a list of those to be contacted when they die or their medical condition changes significantly, but that is relatively rare. People planning to communicate with a larger community need to keep in mind the disabled person's preferences regarding privacy, and if the person is conscious and able to express these preferences, that conversation should be held before any non-obvious communications begin. Often the best arrangements for communication are to designate one person to act as a channel from the next of kin to the rest of the family, friends and colleagues of the incapacitated person. Sometimes the next of kin is too overwhelmed emotionally to cope with this duty. In other cases the communicator has to use his or her best understanding of the indisposed person's sense of privacy and closeness of ties to decide whom to contact. The indisposed person's address book or rolodex can be a starting point for composing a list of people to contact or, if possible, one can find representatives of each group of family or friends to relay significant news. Social media, if the communicator has access to the indisposed person's account, can be helpful. [www.caringbridge.org](http://www.caringbridge.org) is one website that many have used in these circumstances.

**d. Dying:**

When death is near, there often is a clear transition from decline toward death. Some of the earlier signs include withdrawal from people and activities, less communication, less food and liquid intake, difficulty in swallowing generally and in taking medications particularly, and more sleep. Within a week or two of death, often there is frequent disorientation and confusion, symbolic language (such as "I want to go home."), talking to people not in the room, and changes in pulse rate, blood pressure, skin color, breathing, and body temperature, in a total body process. Usually, with this gradual shutting down, pain is not felt as acutely as before. Palliative care to make the patient more comfortable often is the preferred option. Toward the end there may be restlessness, bursts of energy or clarity allowing almost normal communication. If the person's confusion creates a sense of fright or threat, some mild sedation may be appropriate. As death comes close breathing may be shallow, with long pauses, and the person may become unresponsive, with the skin becoming mottled and cooling.

A few people want to die alone, but most are grateful for the caring presence of their nearest and dearest at their bedside. Visits from casual acquaintances should be brief if at all, especially if the dying person seems overwhelmed. Simple presence is more important than what is said or done, although some aspects of comfort care, such as moistening a dry mouth, can



help. If the person is unconscious, people nearby should speak as if the person was awake and listening, as hearing is one of the last senses to go. Sometimes it helps for those near and dear to affirm that it is o.k. for the person to die, that loved ones will carry on afterwards.

As death approaches those closest to the dying person need to think about the choice of the funeral director, undertaker, or cremation service, and the plans for any ceremonies following death. Making these decisions in consultation with the dying person, if possible, can ease that person's mind about those post-death arrangements.

In some religions these last hours of a person's life are commemorated with special prayers. Quakers sometimes hold a meeting for worship at the bedside. Soft music and dimming lights may ease the release from life.

**e. Resources on the body and mind in decline and dying:**

Avonheim, Dr. Judith and Doron Weber, 1992, *Final Passages: Positive Choices for the Dying and Their Loved Ones*, New York: Simon and Schuster for the Philip Lief Group, Inc., 285 pp. *A sympathetic guide to various end-of-life choices, with lots of good reference materials listed.*

**Caring Bridge**, [www.Caringbridge.org](http://www.Caringbridge.org) is a website that facilitates communications about people who are ill, dying, or recently deceased. One can use the website as a basis for, and record of, communications between the nearest and dearest to others who care for and about the person.

**Caring Connections**, (800) 658-8898, is a project funded by the Robert Wood Johnson Foundation, housed in the National Hospice and Palliative Care Organization, <http://www.caringinfo.org>. It provides free information, resources and motivation to learn actively about end of life issues, as a consumer outreach effort. Its advance medical directive forms, available on its website, are kept up to date with local legal requirements, and are recommended for use, perhaps with some modifications to indicate specific preferences.

\*Callahan, M., & Kelley, P. [1992] 1997. **Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying**. New York, Poseiden Press. 239 pp. (2 copies).

Corr, Charles A., Clyde M. Nabe, and Donna M. Corr, 1994, *Death and Dying. Life and Living*, Pacific Grove, CA: Brooks/Publishing Co., 482 pp. + references. *A comprehensive textbook on all the issues associated with death and dying.*

Cox, Donald, 1993, *Hemlock's Cup. The Struggle for Death With Dignity*, Buffalo: Prometheus Books, 311 pp. *A history of the evolution of the right-to-die movement, analyzing many of the issues involved.*

**Compassion and Choices**, P.O. Box 101810, Denver, CO 80250, (800) 247-7421, [www.compassionandchoices.org](http://www.compassionandchoices.org), formerly the Hemlock Society and its Foundation,

## 10 Decline and Approaching Death: Ways to Meet Challenges, 2014 version

*Compassion & Choices improves care and expands choice at the end of life. It supports, educates and advocates.*

\*Dunn, H. 1994. **Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Measures Only, and the Older Patient.** Fairfax, VA. A&A Publishing. 48 pp. (2 copies).

**Death With Dignity National Center**, 520 SW 6th Avenue, Suite 1220 Portland, OR 97204 Phone: 503-228-4415 Fax: 503-967-7064. See more at: <http://www.deathwithdignity.org> . *Suicide and materially helping another to commit suicide are criminal acts in Virginia; even so, this organization offers information on expanded end-of-life choices and promotes legislation to provide options for the dying to control their own end-of-life care.*

Harlos, Mike. 2013. **When Death is Near.** Canadian Virtual Hospice. [http://www.virtualhospice.ca/Html2PdfHandler.ashx?vlink=en\\_US-Main%20Site%20Navigation-Home-Topics-Topics-Final%20Days-When%20Death%20Is%20Near](http://www.virtualhospice.ca/Html2PdfHandler.ashx?vlink=en_US-Main%20Site%20Navigation-Home-Topics-Topics-Final%20Days-When%20Death%20Is%20Near)

Hospice of Santa Cruz County. 2013. **When Death is Near: A Caregiver's Guide,** <http://www.hospicesantacruz.org/HCP.booklet.English.09.pdf>

<http://www.wikihow.com/Prepare-for-the-Death-of-a-Loved-One> . *This Wiki is an accumulation of advice about the steps that help to ease the impact of an impending death.*

<http://dying.about.com/od/thedyingprocess/tp/Preparing-For-A-Death.htm> , a commercial site that has much advice and links for more help in preparing for a loved one's death.

\*Kavanaugh, Robert E., 1972, **Facing Death**, Los Angeles: Nash Publishing, 226 pp. *This personal and sensitive account by a priest explores mourning in America and the complex feelings associated with the end of life. First the dying person needs to receive permission to pass away from every important person he will leave behind. Only then can he voluntarily let go of every person and possession he holds dear.*

\*Kubler-Ross, Dr. Elisabeth, 1969, **On Death and Dying**, New York: Macmillan Publishing Co., 289 pp. *Based on interviews of terminally ill patients, this classic study outlines the six stages through which dying patients progress -- denial, anger and resentment, depression, acceptance, and hope. "The more we are making advancements in science, the more we seem to fear and deny the reality of death."*

Kubler-Ross, Elisabeth -- a variety of titles stemming from her classic, **On Death and Dying** (see above).

\*Levine, S. 1982. **Who Dies? An Investigation of Conscious Living and Conscious Dying.** New York, Doubleday. 317 pp.

<http://www.practicalbioethics.org/mbc-cc.htm> offers detailed tools to help with decisions related to disability and end-of-life issues.

### 3. Care for the Property of Someone Who Is Incapacitated:

When a person is unable, for reasons such as senile dementia, to pay bills and manage his or her property, other trusted relatives, friends, or financial fiduciaries are needed to perform these functions. One can establish joint accounts with rights of survivorship with spouses and others to serve this function, or with an attorney's help one can create a living trust or draw up a power of attorney to authorize someone else to pay bills and manage property. This kind of arrangement can be set up at any time, and one can arrange with one's substitute to leave it on hold or implement it then or at any later time. This flexibility allows one to manage financially as long as one wants to. But powers of attorney customarily expire when one becomes incapacitated, unless the document expresses the intent that they should continue uninterrupted thereafter. These are called "durable" powers of attorney. Even so, all powers of attorney expire at death, as do joint or common holdings unless they have a right of survivorship, as is customary between spouses.

Statutory General Power of Attorney forms for Virginia and Maryland, as well as a DC Power of Attorney provided by a DC pro bono law service, are provided in a pocket behind this document. Other copies of these forms may be downloaded from the resources below. Before using them you may want to check with a lawyer. Links to local lawyer referral agencies are near the end of the document, *Death: Help for Survivors*.

Generally the person paying another's bills and managing his or her property is liable to the beneficiary for all financial decisions, and should avoid any use of the assets for his or her own needs to avoid lawsuits by the beneficiary, the beneficiary's estate or family, and State and local governments. Expenses of administering another person's property, including accountants' and lawyers' fees, can be billed to that property. Proper accounting procedures should be followed. These requirements are much more rigorous for professional financial fiduciaries, that charge accordingly. Of course this kind of asset control includes a duty to meet all of the beneficiary's tax obligations. Other reporting requirements vary by local jurisdiction. Before one does this kind of asset management for another, it is helpful to get the advice of an accountant or attorney about how to manage the property, pay the bills, keep the necessary records, and file the necessary reports.

**a. Resources:**

***i. General Powers of Attorney***

***Virginia:***

**Power of Attorney Instructions and Form,**  
<http://www.formsmax.com/download/virginia-general-power-of-attorney-form.html>

***Maryland:***

12 Decline and Approaching Death: *Ways to Meet Challenges*, 2014 version

Maryland Code, Estates and Trusts Article 17-202: Statutory Form, Personal Financial Power of Attorney: <http://www.oag.state.md.us/Courts/17-202.pdf>

*District of Columbia:*

Financial Durable Power of Attorney Form,  
<http://www.lawhelp.org/dc/resource/frequently-asked-questions-about-general-powe?ref=erh2u>