

Pastoral Care *Newsletter*

*For Member Care Committees,
Ministry and Counsel, Overseers,
and others who provide pastoral care
in unprogrammed Friends' meetings.*

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End-of-Life Planning: How Friends Can Help Those Making Intense Decisions by Martha Morris

As a lawyer, a hospice counselor and a daughter, I have encountered many questions from those who are facing end-of-life decisions. I hope that my experience may be of use to pastoral care givers and others involved in counseling Friends who are dealing with those intense decisions.

Each of us must, sooner or later, face issues relating to death and dying. Our Quaker "how to" manuals, including *Faith and Practice*, encourage us to be responsible, to lift the burden of decision making from the shoulders of others by planning in advance. By making and writing down our decisions, we help to ensure that our wishes will be carried out. While the ideal is advance planning, the meeting often may find itself assisting an individual or family in the depth of a crisis, and wondering how best to help when advance planning is absent.

Pastoral care givers and others working with those in crisis need no special training, though personal experience with death of family members may be helpful. The loving presence of one or more Friends—in a spirit of offering and not of directing—may help the patient and the family to relax and to find their own inner strength.

In my work as a hospice counselor, I felt families were often like swimmers in the shallow end of the pool. Not realizing their legs were long enough to touch bottom, they struggled desperately to stay afloat. I saw my role as offering both information and a calm and loving

presence. I sometimes had to take deep breaths and to take care of myself in those stressful settings.

Often, after a while, family members would almost audibly sigh and relax into the reality of the moment. It was as though they stretched out their legs, found that they reached the bottom of the pool, and realized they could stand. They saw they had within themselves all the strength they needed.

The patient and the family might need to control the nature of the contact with the meeting, especially as death nears. Visits may become burdensome while cards remain welcome. Likewise, patients and families need to retain control over what they wish to discuss and when.

A Meeting's Care

The meeting's pastoral care, whether practical, emotional, or spiritual, can help a member surrender to death. Some may resist death for a variety of reasons; perhaps because they feel they have never received the unconditional love they need or have not reached a state of spiritual comfort. Without specifically attempting to meet these needs, the meeting, through its loving care and assistance, may help a member feel fulfillment and a readiness to die.

The meeting also may offer the support of one or more members in times of family conflict. Out-of-town adult children who have not witnessed a parent's deterioration may not be mentally



Martha Morris

or emotionally prepared to terminate life support. A loving presence, acknowledging their concerns, can help the out-of-towners listen to the necessary information from doctors and to gradually accept the reality of the parent's condition. However, acceptance may not happen immediately.

Friends supporting others under stress may themselves need loving support, though they may not recognize it. Pastoral care givers may need to share thoughts and feelings and experience the support of a team, rather than to carry on, feeling alone. Sharing out of worshipful silence may be especially comforting. The more stressful the family situation is, the more sharing and worship time the pastoral care givers may need. The entire meeting may benefit from extra or focused worship to process a member's dying, if especially stressful. In discussing their own feelings, Friends need to respect the confidences of patients and families.

For those called on by their meeting to deal with end-of-life decision making, three considerations arise:

- First, what are these decisions? What does each entail? Who should be involved or informed in each? Where can further information be obtained?
- Second, how can the meeting assist in the decision-making process?
- Third, how can pastoral care givers help not only with the emotional issues I have described above, but also, with compelling practical matters?

(A caveat: this discussion is general and does not explore the differences among the laws of the various states.)

What decisions are relevant?

Financial matters

Each of us should consider whether a will, trust, revocable trust, or some combination would best meet our needs. Each should decide how to dispose of assets and choose the person who is best suited to act as personal representative or trustee. Listing assets, including location of accounts and documents, can greatly reduce the difficulty and cost of administering the estate. Periodic review of provisions is essential to be sure that the information is up to date. (This is true

for pensions and insurance as well.)

Thoughtful plans for our assets may save survivors much grief as well as money. Who has not heard of a family torn apart while disputing an estate? Even deciding who should get Mother's tea set may be painful and alienating. The most valuable gift we leave our families may be to consider both the emotional and the financial implications of our estate planning.

It is also wise to grant a trusted person durable power of attorney for financial matters, and to designate an alternate, to prepare for possible incompetence, temporary or permanent. If no advance plans are made and a person becomes unable to handle his own affairs, the court can appoint a guardian. Expensive and cumbersome legal proceedings can be avoided by naming one's own choice for this work in a written durable power of attorney. Both the power of attorney and guardianship are valid only during the lifetime of the individual involved.

Although forms for these various documents may be obtained in office supply stores both as kits and software, people are better advised to talk with an attorney who understands tax and other ramifications. If the individual has limited resources and no attorney, he may ask his local country bar association if it has a lawyer referral program which can suggest attorneys who will provide brief legal consultation for a very modest fee. It is important to bring any proposed will forms, prepared questions, or other documents to make good use of a short interview.

Advanced health care directives

These cover general medical decisions (durable power of attorney for health care or the equivalent), termination or rejection of life support (living will), and resuscitation after death (Do Not Resuscitate Order). As long as the patient can decide and communicate, he advises others of his wishes directly. The forms only come into play should the patient become incapacitated.

A health-care surrogate or holder of a durable power of attorney for health care is someone who is empowered to make all health care decisions in the event of the patient's incapacity. Generally, a person who is close to the patient emotionally and geographically is preferable, as is someone who has

the time and the willingness to stay involved. Anyone so appointed needs to feel able to carry out the patient's wishes, such as requesting termination of life support. An alternate also should be named to ensure continuity in the event the original person named becomes unable to serve.

Doctors and hospitals routinely accept decisions of spouses or other close family members when a patient is no longer able to make or communicate decisions and has not designated a surrogate. However, this may not always be the case, especially if there is conflict, as among adult children. Health care providers will generally not substitute the judgment of unrelated partners or friends who have not formally been given a power of attorney or similar authority.

An attorney may prepare the documents, or forms may be obtained from office supply stores or from the National Hospice and Palliative Care Organization (see Resources). The court can be asked to appoint a guardian (of the person, for health care) if the patient has not named a decision-maker while still competent.

Living wills allow each of us to state the types of treatment we consider excessive if we are near death or seriously ill with no hope of recovery. It is appropriate when we are ready to allow the process of dying to proceed naturally. Each of us may request that artificial ventilation, feeding or hydration or other treatments be withheld. The form calls for the name of an individual to carry out these wishes in the event the patient cannot.

Considerations for naming such a person are the same as for the health care power of attorney. A living will not only allows an individual to clearly state his wishes, it also spares family members the pain of trying to guess what the patient would have wanted and encourages them to reach agreement on how to proceed. Orally instructing family members of one's wishes in advance is insufficient, especially if there is disagreement among the family members. Forms meeting the requirements of the state of residence may be obtained from hospitals, hospices, and the National Hospice and Palliative Care Organization (listed among "Resources").

Living wills may also address donation of organs or of the entire body. Anyone considering leaving one's body for medical research or education should

first contact the nearest medical school to learn the conditions and costs, if any, of such donation.

All of the above advanced directives address health care decisions to be made during the patient's lifetime. The Do Not Resuscitate Order (DNRO) is effective only after death. It is a physician's order directing emergency health care workers not to attempt to revive the deceased person. It is usually made when someone is seriously ill and does not wish to be revived only to resume the dying process.

Hospitals typically have their own forms for these orders, which remain in the patient's records. Not every state recognizes out-of-hospital DNROs, though most do. Those states that do may allow the order to be worn as a bracelet or necklace, or may require that it be written on a particular form. Forms for out-of-hospital DNROs may be obtained from the primary care physician or hospice. Care should be taken to prepare and display the DNRO according to the state's requirements.

Make sure the patient, the named decision-makers, and primary physicians have copies of the documents. The DNRO, as a physician's order, may only be acceptable in the original. Since hospitals and even nursing homes may refuse to release the original when a patient goes to another institution or goes home, a doctor may need to complete a new form with each transfer. Since, without a DNRO, ambulance personnel may be required to try to resuscitate anyone who dies in their care, the new form should be completed and provided to the emergency personnel before the patient enters an ambulance.

The most valuable gift we leave our families may be to consider both the emotional and the financial implications of our estate planning.

Long-term care financial issues

In advance of need, Friends may wish to consider whether they would benefit from purchasing long-term care insurance. The state's department of insurance should be able to provide the names of companies offering such policies and perhaps also information to assist consumers. The Health Insurance Association of America also offers a guide. Reverse mortgages can be a source of income when expenses rise, allowing a homeowner to tap into equity.

For a general discussion, Friends are referred to the American Bar Association (ABA) guide. An elder-law specialist may help a family review issues facing

seniors. Names of attorneys specializing in this area may be obtained from the National Association of Elder Law Attorneys, (For these three references, see Resources p. 6).

Hospice: when and why?

This decision can't really be made in advance of need. The physician, Medicare, Medicaid, or private insurance guidelines determine whether the patient's life-limiting illness makes him or her a candidate for hospice. If the patient is enrolled with a hospice, he generally remains in his home or nursing facility. Life-prolonging treatment such as chemotherapy is usually terminated. The hospice nurse focuses on the control of pain and other symptoms, and on keeping the patient comfortable. Other services can include a bath aide, social worker, chaplain, and volunteer. The family is aided both practically and emotionally; they no longer need feel that they walk alone.

A caring and knowledgeable hospice nurse tended my own mother during her final illness. The nurse helped her carry out her plan to stop eating and drinking while remaining comfortable. And I, though an experienced hospice counselor myself, remain deeply grateful for that nurse's sensitivity and understanding which helped me accept my mother's decision.

The patient's doctor may suggest that the time is right for hospice care, or the patient may raise the issue. The reality that death may be near can come as a shock to the patient or family. Even if the terminal diagnosis has long been known and accepted by everyone, the start of hospice care may make the short life expectancy more immediate, requiring adjustment. The meeting's pastoral care givers as well as hospice workers can help the member and family accept and even embrace reality of the transition to a hospice.

Cremation or traditional burial?

Deciding this question in advance of need can spare a grieving family pain and possibly conflict. It may also save money. A person may decide that the money required for his traditional burial would be better spent on a charity or on a grandchild with health or education needs, for example. This practical choice may be much harder for family members to make after the death. Meeting members may be encouraged to investigate funeral and cremation services, to decide, at least, on the type of service and disposition of remains. Friends are reminded to check local laws and ordinances to determine legality of plans for scattering of ashes after cremation.

How can meetings offer practical help?

The meeting may encourage members of its community to consider these issues in advance of need. A small library of relevant resource materials, or a list of websites, telephone numbers and books (together with the public library where they may be found) could help overcome the sense that one doesn't know where to start. (See sidebar, next page) Does the local bar association have a low-cost lawyer referral program? What do local ordinances say about scattering ashes from cremation? What conditions or charges does the closest medical school place on donated bodies? Having such information available (and kept up to date) could be very helpful to members.

The pastoral care committee may invite speakers, sponsor workshops, or invite one of the authorities mentioned in this article, such as a local hospice, to

Questions for Reflection

1. How should pastoral care givers respond to meeting members or families dealing with an end-of-life crisis?
2. What has the meeting done to engage Friends with relevant experience to be on call for those times?
3. How can the meeting help to ease members' and families' spiritual and emotional tension that such a crisis may cause?
4. How can the meeting offer counseling to those who apparently need to make end-of-life decisions, but who may not have been able to face them?
5. What can be done now to assist with advance planning and education?
6. What resources for speakers, workshops, etc. are available from the yearly meeting? From community agencies and organizations? From government sources?

provide an advice session for older Friends.

The meeting may provide a form, asking members to inform them of any matters in which the meeting is asked to take a hand, e.g., memorial service preferences or even health care decision making for a member with no family. It is useful for the meeting to know the name, relationship and contact information for the decision maker(s), even for a member whose family will handle all of the issues considered in this article. This helps prevent confusion at the time of death.

The meeting may be called upon to support a member (or her family) facing imminent death who has not yet made all these decisions. The availability of resource information may be especially useful in this instance. A member receiving hospice care or who is in a hospital or nursing facility should have a social worker who can also provide very practical assistance.

The meeting may be able to provide an experienced Friend to help the member make and communicate his or her decisions. If a family is experiencing great uncertainty or even conflict, a

clearness committee may be helpful. Whether the family is Quaker or not, they may welcome moments of silence or group prayer.

Discussion of practical issues may open the door for the meeting to share feelings and ideas about death and dying, perhaps at a short retreat. By opening discussion of these subjects in advance of need, pastoral care givers may help members feel grounded enough to make their own decisions.

And, just as important, the meeting itself may grow in depth and in love by caring for members and families as they seek to find their way through an imminent crisis. May it be so for all of you.

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Martha Morris graduated from George School (1964), Swarthmore College (1969) and the University of Pennsylvania Law School (1974). She practiced law in suburban Philadelphia before moving to Central Florida to assist her elderly parents. There she earned a master's degree in mental health counseling (Rollins College, 1995) and worked as a hospice counselor. She is now retired, a "professional volunteer," and a member of Winter Park Monthly Meeting.

One Meeting's Experience:

Langley Hill (VA) Meeting Creates Needed Information Packet

by John Surr

Some years ago, a small group from Langley Hill Monthly Meeting gathered to consider what we could do for Friends who were facing final illnesses for themselves or others, as well as for those whose nearest and dearest had died. Langley Hill is a mid-sized, unprogrammed meeting located in McLean, VA, a suburb of Washington, DC.

Our meeting member, David Scull, initiated the process. Several members of our meeting had gone through these experiences and we wanted to be able to do more than hold memorial meetings for them. We created a small packet with information about living wills, durable powers of attorney, and other advance directives, as well as wills, the grieving process, and the like. This packet was offered for a small donation to cover printing expenses.

While most members may have been unaware of the project even after it was announced, others who were facing a death in the family, or perhaps were preparing for their own death, found the information very helpful. As others encountered the need in their lives, it was immediately available. Since then,

the packet has been reviewed and revised by an ad-hoc committee, at about ten-year intervals, under supervision by or in consultation with the Committee for Care and Clearness (or its predecessor, the Committee on Oversight and Family Relations).

The materials include queries on preparing for death, discussions of accident information and advance directives, wills, local (VA, MD, and DC) laws governing intestate estates, avoiding probate, preparatory information for the meeting and the family, and some suggestions to help survivors after a death. The latest revision (2005) is available online (see Resources, p 6).

Pastoral care givers should know that some very valuable forms, not available online, are included in a printed (hard copy) packet. (See Resources.) They cover information needed following an accident, advance directives, information for meeting records, personal information for a death certificate, contact information for those to be notified of one's death, offices to be called in the event of death, information for an obituary, and a list for outstanding obligations.

Its popularity among Langley Hill Friends and their friends has necessitated two printings.

In our process, we have drawn upon the experience of other meetings in Baltimore Yearly Meeting, such as Sandy Spring Friends Meeting and Midlothian Friends Meeting. We also consulted a wide variety of national and regional organizations as well as printed materials.

Our work has been complicated by the fact that Langley Hill's attenders come from three different states—northern Virginia, Maryland, and DC—each of which has its own rules, forms, and procedures concerning final illnesses and death. Although there has been some standardization among advance directives, pastoral caregivers should advise members to consult a local estate-planning lawyer before the meeting uses or publishes a form that may be, or may become obsolete or inappropriate to the jurisdiction.

Langley Hill Friends Meeting has considered plans to hold gatherings in each of the three jurisdictions it serves, attended by a local estate planning lawyer, where Friends would be encouraged to draw up and even sign their own advance directives, wills, etc., with expert consultation and community support. These plans have not proceeded very far, mostly due to difficulties in assembling enough Friends from each jurisdiction to make it worthwhile for an estate lawyer to donate his time and expertise. A meeting whose members are within the borders of a single state will have the advantage of dealing with but one set of laws and regulations.

Our packet should be reviewed and revised as the laws, practices, and web site information about final illnesses and death tend to change. While there is no formal mechanism for initiating a new review, Langley Hill Friends Meeting has benefited from a continuity of individuals who have been involved in these reviews.

We feel that the packet has been very helpful in raising consciousness about the practical issues around death and final illnesses. Knowing it has served Friends in a time of special need makes it well worth

the occasional efforts to keep it up to date and to distribute it.

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John Surr, a recovering lawyer, is recording clerk of Langley Hill Friends Meeting and formerly its clerk. At various times he was co-clerk and a member of the meeting's committee providing pastoral care. Friends may contact him at surr@bis.com.

Resources

The American Bar Association Family Legal Guide, Third Edition, (2004),

The Consumer's Practical Guide to Funerals, Burials & Cremation, Scott D. Emmert. (American Literary Press, Baltimore, MD, 2005).

Funerals: A Consumer Guide, Federal Trade Commission; www.FTC.gov ; 1-877-FTC-HELP (toll-free).

Grave Matters, Mark Harris. (Scribner, New York, 2007).

A Guide to Long-Term Care Insurance, Health Insurance Association of America at www.hiaa.org.

Planning for End-of-Life Events, (hard copy, with forms) John Surr, 8217 Lilly Stone Drive, Bethesda, MD 20817, suggested donation \$5 or online (without forms) http://www.quaker.org/langleyhill/planning_for_end_of_life_events.html

National Hospice and Palliative Care Organization; www.nhpco.org <http://www.nhpco.org/>; 1-800-658-8898. State-specific forms.

Funeral Consumers Alliance, www.funerals.org.

National Grief Support Services, <http://www.griefsupportservices.org>

*Funeral Consumers Alliance, www.funerals.org
National Hospice and Palliative Care Organization, <http://www.caringinfo.org>*

National Grief Support Services, <http://www.griefsupportservices.org>

Dealing Creatively With Death: A Manual of Death Education and Simple Burial, by Ernest Morgan, Jenifer Morgan, Upper Access Books, 2001

Next Issue: January 2009 Planning the Memorial Service by Sue Heath

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