

*Quaker values
& end-of-life
decision making*

WORKBOOK

*This booklet is written by Friends, for Friends, to enable them
to make informed decisions about what end-of-life care they want,
with the guidance of Friends' values.*

Name _____ Date _____

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The ARCH Program is funded in part by a grant
from the Friends Foundation for the Aging.

©2016 ARCH ISBN 978-0-692-58838-3



Welcome

to this workbook designed by Friends to assist those in the Religious Society of Friends in making decisions about their end-of-life care and to provide examples of the forms that ensure their decisions are followed.

What's in here?

This booklet contains exercises and information to help you make informed decisions about what care you want at the end of life and about the best possible decisions for you. It will also help you choose your health care proxy, a person who is enabled to make health care decisions when you can't, or don't want to.

Once you have reflected on these choices, you'll complete a Health Care Proxy form designed with Friends in mind, contained in this booklet. The Proxy form is a legal document where you specify your health care agent and make your wishes known.*

We have also included discussion of the Do Not Resuscitate form (DNR) and the MOLST/POLST form (Medical/Physician Orders for Life Sustaining Treatment). These forms can be obtained from your health care provider, and we'll explain each one as we come to it.

Why do I need to complete these forms?

We all have times in our lives when we are too sick or too injured to make our own medical decisions. And we've all heard stories of families who could not come to a decision with which everyone was comfortable because they didn't know what their loved one would want.

Those you care about most in the world will be grateful that you've made your wishes clearly known. Completing a Health Care Proxy and other Advance Directives will save them the anxiety of not knowing what you would have wanted. At a time of great stress you have not added to it by neglecting to complete these few, simple forms.

*Not accepted in these states, but you can search the internet for their forms: Alabama, Indiana, Kansas, New Hampshire, Ohio, Oregon, Texas and Utah. The form in this workbook is acceptable in all other states.

Who needs to complete these forms?

Everyone 18 and over needs to complete Advance Directives. Whether it's a 20 year-old who has fallen off a motorcycle, a 50 year-old suddenly unconscious, or a terminally ill 90 year-old, each of us owes it to our loved ones to think through our own wishes for our end of life. Some families make a gift of Advance Directives as part of high school graduation or a wedding.

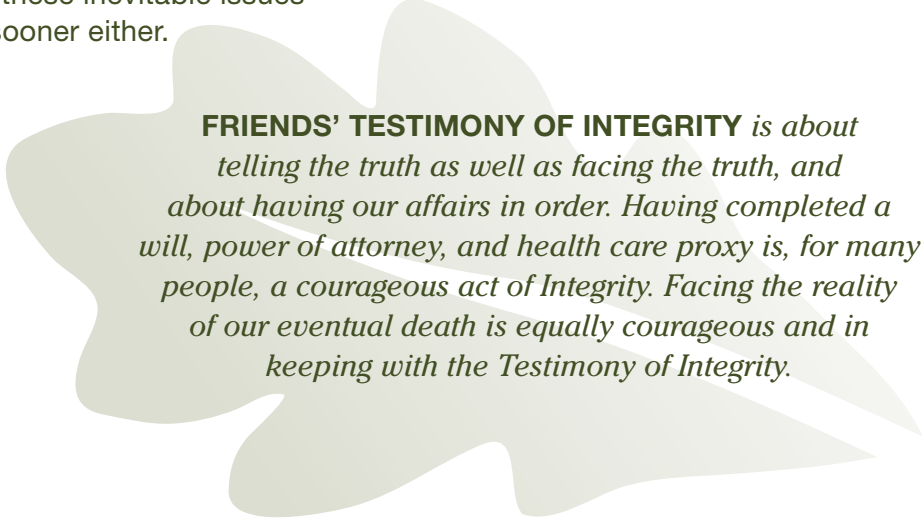
Don't I need a lawyer to do this for me?

No. The legislatures of each state have designed these forms to be easily understood and not to require a lawyer's intervention.

Do Friends have any guidance on Advance Directives?

As we proceed through this booklet, we will draw your attention to Friends' Testimonies and other wisdom and guidance as an ethical and moral framework for your decisions.

These can be difficult things to think or talk about, but you should do it anyway. Refusing to think or talk about diminishment and death won't keep those events from happening eventually. Talking about these inevitable issues won't make them come sooner either.



FRIENDS' TESTIMONY OF INTEGRITY *is about telling the truth as well as facing the truth, and about having our affairs in order. Having completed a will, power of attorney, and health care proxy is, for many people, a courageous act of Integrity. Facing the reality of our eventual death is equally courageous and in keeping with the Testimony of Integrity.*

Can I do this with my Quaker Meeting?

Completing this workbook together is rewarding for Meeting members to undertake as a group. You'll want to include opportunities for reflection, writing, sharing in small groups and with the group as a whole, but do not try to cover this entire workbook in one or even two sessions – there is too much to think and talk about. A better pace is about five sessions.

To start, name a Health Care Agent

A health care agent is the person with the responsibility to follow your wishes as indicated on your health care proxy form.

Begin with choosing one person as your health care agent. Naming two can lead to difficulties, but having an alternate in case your health care agent is unavailable is a good idea. The Health

Care Proxy form has a section for naming your agent and an alternate who can fill in for your agent if that person is not available.

- It does not have to be your oldest child, or a son, or a spouse. Choose someone who is competent, at ease talking with you about these issues and comfortable with following your wishes. That might be a friend, a more distant relative, or someone from Meeting. It is a good idea to choose someone likely to outlive you.
- Choose someone who lives close by or is able to come to your bedside quickly.
- Select an agent who can be cool-headed, who is willing to follow your wishes, not their own; someone who can be assertive, but not antagonistic.
- Your agent must be over 18 and they can't be your physician or an employee of your health care facility.
- Be sure to inform your agent that you have named them and ask if they are comfortable with this responsibility – we have heard of health care agents who learned they had been selected for this role only when they arrived at the hospital.

CASE NOTES: *At 25, Gary had given no thought to a health care proxy. His car accident left his parents and his partner struggling over both who would get to make medical decisions and what Gary might want.*

FRIEND'S PEACE TESTIMONY *asks us to live in a way that avoids the occasion of war. Advance Directives avoid arguments between loved ones: your decisions and your chosen agent are known ahead of time.*

The next step is reflection

You need to consider how you would like your dying and death to be, what would make it meaningful, positive and peaceful. It is often helpful to reflect on the deaths and funerals of people who you were close to, especially early in your life. Our unspoken values are often formed by those early events. Be sure to share your reflections with your agent, your loved ones, and your Meeting.

Questions for reflection

1. What would you describe as a “good death”? _____

2. When I think of the dying and death of (name) _____, I always remember

3. Therefore, my hopes for the end of my life are _____

4. My fears are _____

5. I want _____

6. I do not want _____

CASE NOTES: *Fred is over 90 and has been telling his family for some time he is ready to go. His heart is weakened, he is short of breath and losing what little energy he had. One morning he can't get out of bed. His wife is beside him, holding his hand. His daughter calls, hears about Fred, and since she lives in another state and hasn't been a part of these conversations, calls the ambulance. In the emergency room the MD talks the family into a pacemaker for Fred. If you were Fred's family, what would you do? If you were Fred what would you want?*

What is important to you at the end of life?

There are no right or wrong answers, just your personal preferences, and your answers are likely to change over your lifetime.

(Circle true or false)

True / False – I want to tell my story, such as having someone write it down for me or having it recorded in audio or video.

True / False – If I don't know who I am or who you are, I want to be let go.

True / False – If I am dying/failing, I only want antibiotics if they will prolong my living, not just prolong my dying.

True / False – Physical comfort is most important, even if it means I might die sooner.

True / False – I want to be alert as long as possible, even if it means I will be in pain.

True / False – I want to be kept alive until my family can get to my bedside, even if that will be several days.

True / False – I want to die at home.

True / False – I don't want to be kept alive on machines if I'm not going to recover.

True / False – I don't want a feeding tube.

True / False – I want to be kept alive as long as possible.

True / False – If I've said I want to go, I mean it.

Are there circumstances in which you would want to stop, or not start, treatment designed to prolong your life? What are they? _____

If the only means for you to continue living is with a machine breathing for you, which would prevent you speaking, and/or tubal feeding or dialysis, what would you want done? _____

Would you want it continued indefinitely? _____

A HEALTH CARE PROXY for FRIENDS

Guidelines on following page. Please print.

1. I, (my name) _____

2. appoint (agent name) _____

(address) _____

(phone) _____ (email) _____

as my health care agent to make all health care decisions for me, unless I say otherwise. This Proxy takes effect when I can't or don't want to make health care decisions for myself.

3. Optional directions: My health care agent is to make decisions according to my preferences, as stated here or as I have personally informed him/her previously. *(Attach additional pages if needed.)* My agent has my permission to make any decisions about food and fluids (artificial nutrition and hydration/feeding tubes), as well as agree to, refuse, or stop life-sustaining treatment.

4. A substitute who can fill in for my agent if my agent isn't able or willing to make health care decisions for me:

Name _____

Address: _____

Phone: _____ Email: _____

5. My signature _____ Date _____

My address _____

6. Witness 1 _____

Address _____

7. Witness 2 _____

Address _____

How to complete the Health Care Proxy

1. Print your name on line 1, you will sign on line 5.
2. This form is the *health care proxy*; the person you name is your *health care agent*.
3. You must say that your agent has the right to make decisions about food and fluids, and about starting and stopping any life-sustaining treatment. In addition, this is the place to add, or attach additional pages, with any other directions you want. Remember that circumstances in the hospital can be different than anything you and your agent imagined: the more specific your instructions, the less leeway your agent has to make decisions on the spot.

It is probably better to discuss with your agent various scenarios rather than think you can cover everything in writing. If you wanted to limit your agent's authority in any way, this is where you would do it.

4. On the off chance that your proxy is away, ill, or in the same accident you were, it is important to have a substitute, and to have these same conversations with that person.
5. Signing and dating the form makes it legal. Be sure to add your address. If you cannot sign, you can direct someone to sign for you. Either way, the signing is done in the presence of the two witnesses in section 6.
6. You need 2 witnesses, over the age of 18, and they can't be your physician or an employee of your health care facility.

Can I ever change my mind about my proxy, agent, or the care I want?

Yes. You can write "revoked" and the date on your previous Advance Directives, or destroy all previous copies. Send the revised forms to your agent and to anyone else you've shared copies with.

I live half the time in another state – will they honor this proxy?

We recommend that if you spend time in a state that does not accept this proxy (Alabama, Indiana, Kansas, New Hampshire, Ohio, Oregon, Texas and Utah), that you fill out a state-specific proxy form for both states and have them agree with each other. That is, both should designate the same person as your agent, and the same outline of the care you want. Each state's forms can be easily found online by searching "[State Name] health care proxy." For example: "New York State health care proxy".

Who should have a copy of these forms?

You should keep the original and give a copy to your agent, your family and friends, your Meeting, and all your medical providers. Also bring a copy every time you are admitted to a hospital. Many people keep these and other records in a notebook at home, making sure those they trust know the location. We have also included a wallet size proxy form on page 23, so you'll never be without one.

How specific does my proxy need to be?

It is important that the proxy document include the right for your agent to withdraw treatment and to refuse or withdraw food and fluids. In some states, the hospital will insist on food and fluids by tube unless your agent is given specific permission to withhold or withdraw them.

If you no longer want, or are unable to eat, withholding or withdrawing food and fluids can be a painless way to be allowed to die. Insisting on food and fluids when you are at that point can cause pain as the body may no longer be able to digest.

When your agent has to make such difficult decisions, she/he can get advice from the people caring for you, including your spiritual care provider. Most importantly, your agent needs to ask: am I prolonging living, or am I prolonging dying?

At what age is a health care proxy needed?

These days it is common to be required to fill out a health care proxy on entering a hospital for any reason, and senior housing facilities usually want to have one on file too. This leads many to mistakenly think that they only need a proxy when they are old or sick, when the reality is that we all need a proxy and a power of attorney when we turn 18. Parents can make the proxy form a coming of age birthday gift as it recognizes that the child is now an adult. This foresight helps prevent divorced parents from arguing over their child's care in hospital hallways, and allows the young person to choose whether a parent or a partner makes critical medical decisions.

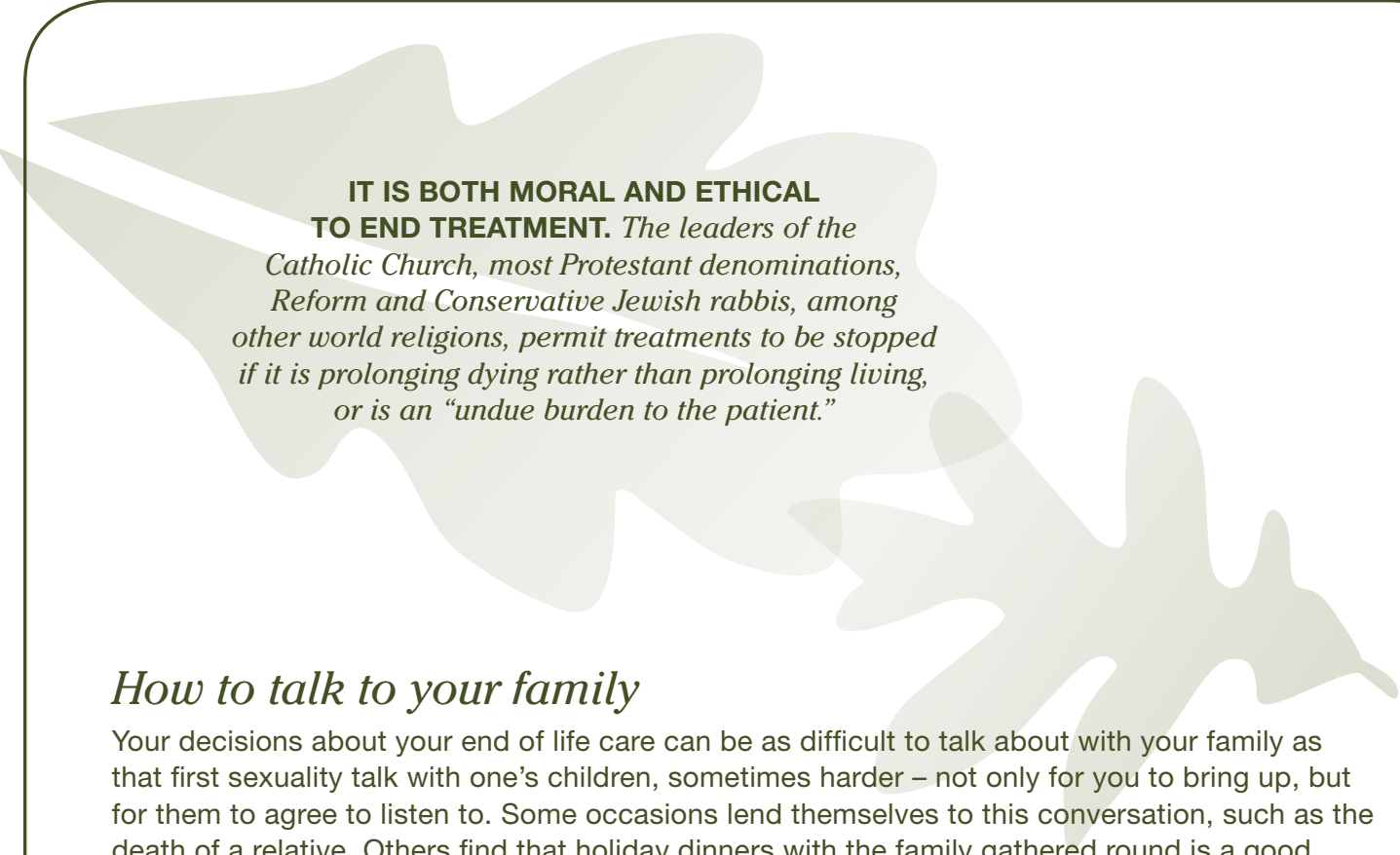
Living Will or Health Care Proxy?

Living wills have been around longer than health care proxies, and many people are more familiar with that term. But states view the proxy as the primary legal document – living wills are not necessary if you have a proxy. If you decide to have both, make certain that your instructions are the same on both documents. You can use a living will form to guide your agent about your wishes.

CASE NOTES: *Phil, 78, was in the hospital with an infection around his heart; his daughter thought he seemed better when she saw him that afternoon, but 6 hours later his heart stopped. The hospital tried to resuscitate him and called the daughter, his agent, to ask if she wanted them to try again. Because she lived an hour away, she had to make the decision over the phone. She decided they should use the electric paddles on his heart again...and again...and again. After 10 or 11 unsuccessful tries, the physician said they were ending treatment. If you were Phil's daughter what would you do? What would you wish Phil had done?*

REALITY CHECK: According to surveys, most of us want to die at home, but 1 in 3 cancer patients die in a hospital. Most of us (76%) want to die quickly but 73% of us will actually die of a lingering illness or general decline. Almost all of our care is provided by family – 90%. Of the remainder, 7% is provided by your congregation, only the last 3% is provided by paid caregivers.

Most of us don't realize how physically traumatic and potentially painful resuscitation of the heart is using electric paddles (AED), or that the rate of survival for those over 70 after the procedure is less than 3%; for those over 50 it is less than 20%. Heart resuscitation was designed for young, fit men on a battle field, not for seniors and the seriously ill.



IT IS BOTH MORAL AND ETHICAL TO END TREATMENT. *The leaders of the Catholic Church, most Protestant denominations, Reform and Conservative Jewish rabbis, among other world religions, permit treatments to be stopped if it is prolonging dying rather than prolonging living, or is an “undue burden to the patient.”*

How to talk to your family

Your decisions about your end of life care can be as difficult to talk about with your family as that first sexuality talk with one’s children, sometimes harder – not only for you to bring up, but for them to agree to listen to. Some occasions lend themselves to this conversation, such as the death of a relative. Others find that holiday dinners with the family gathered round is a good opportunity, right after dessert, before the table is cleared and the big game comes on.

CASE NOTES: *Annette knew she needed to have ‘the second talk’ with her son when he was home for Thanksgiving, but her husband didn’t want to have it over dinner, so Annette introduced the topic in a matter-of-fact tone while her son helped her set the table. By the time dinner was ready the conversation was completed.*

It is important to talk to all of your immediate family so that everyone is on board with your wishes, rather than only your agent knowing what you want done, so that any questions – or arguments – are dealt with before hand. It is particularly important for out of town family to know your wishes and be kept up to date on your condition.

Hospital staff have all experienced the arrival of the out of town relative who starts demanding additional treatment, even when it will not change the prognosis. Often this relative is simply in the dark about the patient’s thinking about the care they did, and did not, want at the end of life. With smart phones now so readily available, sending out-of-town family a visual update frequently enables them to see the progress, or lack of progress, of their loved one. Smart phones can also record a conversation with the doctor. Hospitals have social workers, chaplains, and ombudsmen that can help the family through these difficult discussions.

Besides having “the second talk,” it is necessary to have all the documents where your family can find them. Often that is a notebook or file in your bedroom or office. Remind your family where you keep it, and be conscientious about keeping it updated.

CASE NOTES: *Arlene's mother kept a blue notebook in her room. When her mother's doctor said mom needed to go to a nursing home, Arlene took down the notebook so she could let the nursing home know what mom's assets were. When mom died 3 weeks later, Arlene found that there were additional bank accounts as well as safety deposit boxes whose keys weren't all found. Mom had not kept all the information in one place and up to date.*

MOLST or POLST

Some medical providers want to do everything possible, even after there is any hope of benefit for the patient. The person who is your agent can refuse treatment and can have you “discharged against medical advice” so that you can die at home, not connected to machines. Hospice is of great help in such circumstances.

Honoring patient preferences is a critical element in providing quality end-of-life care. To help physicians and other health care providers discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment, more and more states are adopting Medical (Or Physician) Orders for Life-Sustaining Treatment (MOLST or POLST). They are only appropriate when you have a very serious health condition and:

- want to avoid or receive any or all life-sustaining treatment;
- reside in a long-term care facility or require long-term care services; and/or...
- might die within the next year.

To complete a M/POLST form, you and your physician discuss your prognosis, treatment outlook, and your wishes. It is your opportunity to be clear with your medical providers and for them to acknowledge that they have been informed of those wishes.

DNR

Do Not Resuscitate (DNR) orders direct medical providers to refrain from invasive or heroic medical measures to prolong life. They usually also refer to forgoing antibiotics. MOLST and POLST contain sections for DNR decisions. A DNR is appropriate when a person is towards the end of life, and not before. Forms can be found on line: make sure you get the one for your state.

Paramedics are often required to honor a DNR (check your state's regulations). Therefore, it ought to be readily available in the home and go with the patient if they are transported to the hospital. Put it on the refrigerator door; put a small sign on the front door. For times you are away from home, you may want to wear a DNR bracelet.

Proxies and Living Wills will not be accepted by paramedics, only official DNR orders. If you are nearing death at home and have a DNR order, instruct your loved ones that they can hold your hand, sing, pray, tell you they love you— anything except calling the paramedics. There will be time later to deal with medical personnel. This may be very difficult for them to do in the moment. It is important that you have a mutual understanding of this difficulty, so this discussion is as important as the form itself.

Power of Attorney

A Power of Attorney (POA) lets someone sign your checks, pay your bills, and generally keep things running at home, or make the arrangements for your placement in a facility or burial. Each state has their own form; simple ones can often be purchased at office supply stores or found on line. States with more complex forms may require a lawyer.

Choose someone entirely trustworthy, someone who won't be tempted by having access to your bank account or the ability to sell your house. Again, this does not have to be a relative; it would be better not to have the same person who is your health care agent, as that person will be busy enough. Choose someone who is good at managing their own finances. You can rescind a POA by sending the person a notarized statement to that effect.

Types of POAs

One type of POA goes in effect immediately and ends when the person becomes incompetent. This is a *non-durable* POA.

There are POAs that go into effect immediately and end with the death of the person. This is a *durable* POA.

There is also a *springing* POA so that the power is only transferred when the person is declared incompetent. Some feel more comfortable using this type; find out if it's available in your state. Some states call their health care proxy forms *medical powers of attorney*.

THE TESTIMONY OF STEWARDSHIP reminds Friends that we have a responsibility to rightly use the earth, our bodies, our time, as well as our money. This testimony should be central to our burial planning, our use of medical procedures at the end of life, and the expectations we place on our caregivers, proxies, and those we ask to be our POAs.

Where does hospice care fit in?

Call hospice early in the process – they will let you know if it's time for them to be involved. Then, when you do need them, you've already made the initial contact. Don't deny your loved one – or yourself – the support and information that hospice provides. Plus, statistics show that those on hospice care live longer than those without. Hospice is about making each day the best day possible, and as pain-free as possible.

Hospice care is covered by Medicare and many insurance carriers; its services include nurses, aides, volunteers, social workers, and a chaplain. Hospice evaluates the referral, decides what support is appropriate for each household, and changes or increases services as needed. On average, hospice is contacted too late to provide the full range of services: most families invite hospice when there is less than a week left.

CASE NOTES: *Louise (90) knew she was dying and knew she wanted hospice involved. When her daughter first called hospice it was decided that Louise did not need their services yet since her daughter lived with her. A few months passed and the daughter realized her mother was becoming weaker, so she called hospice for a second evaluation. This time they agreed that Louise would benefit from their involvement, but with the daughter on-site, it was left for a hospice volunteer to pull the weeds from Louise's flowers and give her a foot bath. As the months passed, hospice staff added more services and was able to tell her daughter when it was time to bring the rest of the family to Louise's bedside. They spent those last hours at Louise's side taking turns holding her hand and telling her how loved she was.*

Accepting help

Accept all the help anyone offers. Make a list of things that would be helpful, such as a meal, grocery store run, picking up meds, doing laundry, or keeping you company while your caregiver naps, gets a haircut, or walks in the park. Being a caregiver is physically and mentally exhausting, so don't wait until the breaking point before accepting help.

You may wish to think of yourself as independent but you aren't, none of us are: we are all interdependent on our community and always have been.

THE TESTIMONY OF COMMUNITY *is that fellow feeling we all experience after worship that naturally gives rise to care and support for each other. Meetings still provide or arrange for much of the care and support needed by members and attenders. Friends are very good at giving help, and not so good at receiving it. However, it is in giving and receiving help that we live out the Testimony of Community. Quaker Parker Palmer has written, "The most generous thing we can do is to receive help." How can we deny others this opportunity of grace?*

Old customs new again

The practice of vigiling is being rediscovered. For centuries it was the custom for family members to sit with the person dying, through the day and night. Often a friend or neighbor would take the overnight duty to give the family time to rest. They would say, "I sat up with..." or "I kept watch for..."

These days, there are training programs to help us relearn what everyone used to know. The trained vigiler can help the family emotionally and create a sacred space for the dying person.

Another practice being rediscovered and taught is called "Death Midwives." This specially trained person comes to the house to prepare the body for burial, or to show the family how to perform this loving task. Additionally, a death midwife can enable the family to have the viewing at home with the use of dry ice.

Body donation

Medical schools are always in need of bodies for dissection by medical students, and bodies are often in short supply. You can donate your body to your closest medical school, and they will transport it, usually up to 50 miles, sometimes further, usually at no cost to your family. The medical students are taught to treat the body with respect and gratitude, and the following year the medical students will conduct a memorial service honoring those who aided their learning, often with poetry and music, after which the remains are buried or returned to the family. Many Friends choose body donation because it is both free and generous, as well as in keeping with our Testimony of Simplicity.

Embalming

It is important to know that no state requires embalming. Also know that Muslims and Orthodox Jews consider the process of embalming to be a desecration of the body. The embalming fluids are released into community sewers and eventually seep into the ground water under the cemetery. Also, there are now essential oils that serve the function of preservation of the body for viewing, a much greener choice.

Note that vaults will not protect against leakage of embalming fluids into the ground and water table indefinitely. Vaults are largely for the convenience of the cemetery: they make mowing easier because they keep the ground level. Some vaults are open on the bottom, keeping the cemetery owners happy while still allowing the body to become part of the earth.

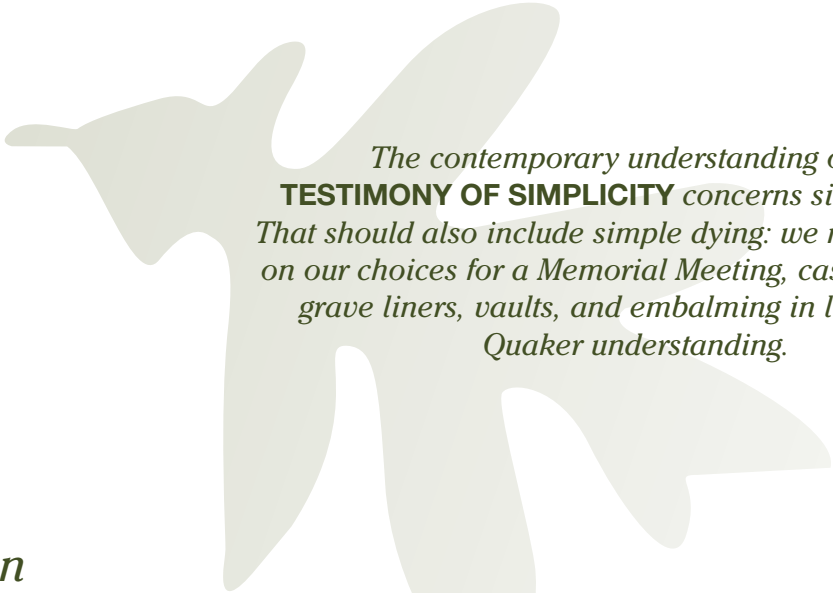
Green burials

The green burial movement is rather new and grows out of a sense that we need to be good stewards of the earth in death as in life. It neither embalms nor cremates, but commits the body directly into the ground in a space designated for this purpose, such as a farm, conservation area, or an area set aside in a conventional cemetery. If you choose to have a green burial, be sure to inform your family and your Meeting.

There are simple tasteful containers for the body that will biodegrade, such as wicker and cardboard. A simple pine box can be purchased ahead of time, or the plans for making one yourself. Some states allow the body to be put directly into the ground. Shrouds and patterns for shrouds are also available on line.

Your state regulates cemeteries but local ordinances regulate burials: check with local authorities on what is, and is not, allowed. Some states still permit burial on family-owned land.

Low cost coffins and caskets exactly like the ones at the funeral home can be ordered on line and shipped the same day. Federal law requires that funeral homes accept a coffin you have purchased elsewhere.



*The contemporary understanding of the
TESTIMONY OF SIMPLICITY concerns simple living.
That should also include simple dying: we need to reflect
on our choices for a Memorial Meeting, casket or coffin,
grave liners, vaults, and embalming in light of this
Quaker understanding.*

Cremation

Each year, more Americans choose cremation as a greener option. While that is true, it is not the greenest choice: one cremation uses as much energy in the form of gas and electricity as a 500 mile car trip, and releases a staggering 882 pounds of carbon dioxide into the atmosphere, not to mention mercury vapor and other pollutants. Green burial is the greener option.

Prepaid funerals

In some cases it may be expedient to prepay funeral expenses. It saves your family from wondering what you'd like, and it will make you Medicaid eligible sooner. Be sure the money is put in an escrow account by the funeral home so that it is in your name. If the funeral home is sold to another company, the account is not an asset of the funeral home but still your property; also make sure that any interest earned is added to your account. In addition, make certain that you can't take the money out of that account at any time in the future; otherwise it can be included in calculating your eligibility for Medicaid, should the need arise.

Friends' memorial meetings

As you may know, Friends' traditional practice is to have a very private burial with only close family. Later, at the convenience of the family, a Memorial Meeting is held which is a Meeting for Worship. This Meeting is open to all, the Memorial Minute is sometimes read, and those attending have the opportunity to speak out of the silence.

The Friends General Conference Bookstore carries a very inexpensive leaflet, *Friends Memorial Meeting for Worship*. It is useful to have these available for the non-Friends as they arrive at the Memorial Meeting. Often light refreshments are served at the conclusion, giving those attending an added moment to share stories with others.

CASE NOTES: *Margaret told her Meeting not to have a Memorial Meeting when she died. Not fair! Your Meeting, friends and family need to have a Memorial Meeting as part of their grieving and to have a sense of closure. We all need to have time together to share our loss in community. This is an ancient human need. You won't be there – why deny others this important time?*

Memorial minutes

A memorial minute is usually written by someone in Meeting other than the family, although family will need to be consulted. It is not an obituary, although currently it contains much of the same information. Friends' tradition is that the memorial minute is a record of the person's spiritual journey and their particular spiritual gifts and contributions to improving the world. I'm sure we've all seen memorial minutes published in Friends Journal that can serve as a template. Memorial minutes appropriate for publication in Friends Journal are generally for those who have been members of Meetings in other Yearly Meetings or whose reputation as a Friend is widely known.

Memorial minutes are often read at the Regional Meeting level and can be read at Yearly Meeting if the person was active at that level.

CASE NOTES: *Rose was the only Friend in her family. When she died, her family didn't know anything about Friends' practice so they neither contacted the Meeting nor had a memorial minute. Make sure your family has your Meeting's contact information.*

Leaving a legacy

Have you noticed that a certain refrain in conversations towards the end of life or at the memorial sounds something like this: "she was the best teacher I ever had"; "he developed a new way to do the work that made a big difference"; "she'll always be remembered for..."; "he was a wonderful..."

Whether it is tangible, like a park bench, or intangible like the hours we volunteered, it is important to most of us to identify the legacy we leave behind. We may know what it is we want to be remembered for, in which case it is comforting to have visitors acknowledge that gift to the world.

For some, though, what that legacy might be is harder to name. In that case, it is a spiritual gift to help the person to name the legacy that you see as significant, or to help them tease out what their legacy might be: "you've been a wonderful Mom"; "think of all those hours you put in at Little League"; "you taught me to sew...or fish...or grow vegetables..."

Some grandparents (or parents) are afraid that their little ones won't remember them. Loved ones can help record their life story in audio or video; assist in putting together a photo album; save a box of items that will help the young ones to someday know the loved one who has passed; have a quilt made out of grandpa's shirts or grandma's aprons, or a pillow from ties; use jewelry to create a bauble for the Christmas tree; donate a tree to the community; plant bulbs. Do not gather up the clothes of the deceased until all the family is ready. Remembrances can aid in grieving and are meaningful at memorials and family gatherings.

CASE NOTES: *When Laura died, her son was only 4 and everyone was concerned that he wouldn't remember her. His grandparents packed 2 large boxes of mementos: cartoons off the fridge, her belly dancing costume, the cactus-shaped plastic wine glass, her Phi Beta Kappa key. At 22, he at least has a sense of what kind of person she was.*

Organ donation as part of your legacy?

There is no absolute age limit for organ donation. In general, organs may be donated from a newborn or someone as old as 75, depending on the tissue in question. The age limit for donation is below 80 for corneas and between 16 and 60 for long bones. There is no age limit for skin donation. Donations are not accepted from those with HIV, cancer, or an active infection.

The transplant program, recipient's insurance, or the recipient should cover your expenses from tests and hospital costs related to organ donation. There is no cost to you as an organ donor.

Your costs under Medicare as an organ recipient

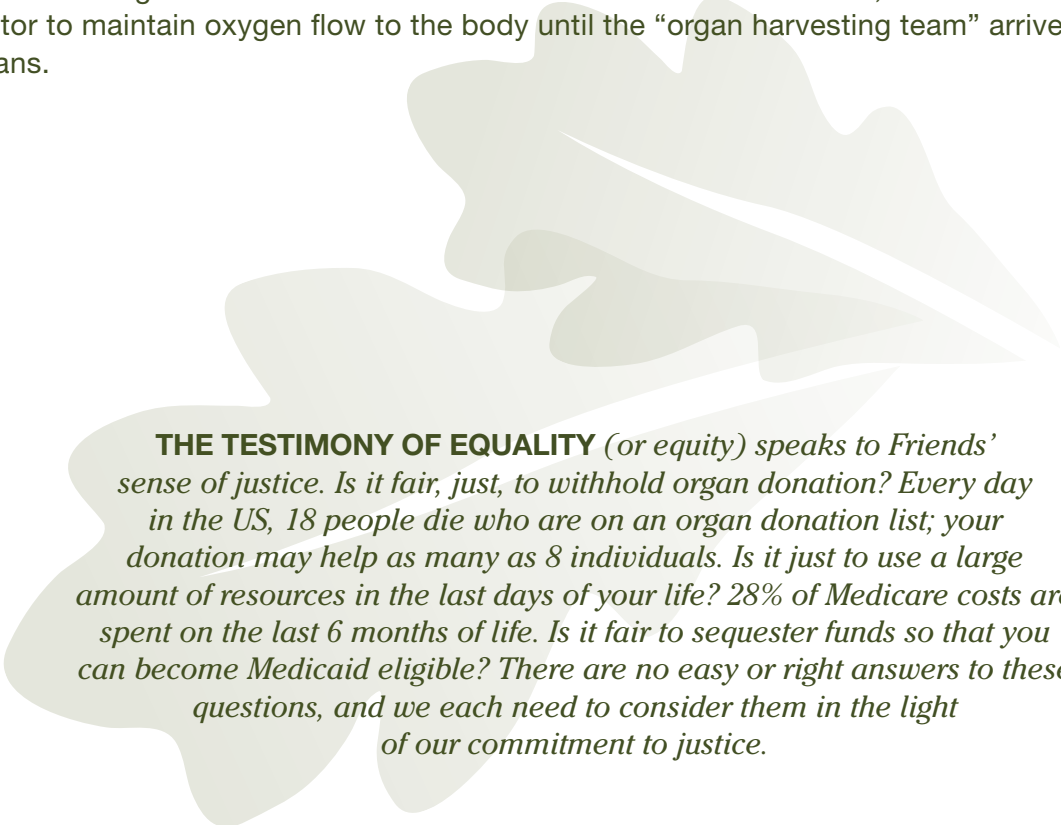
Medicare will cover most organ transplants provided there is a reasonable likelihood of it extending your life. Medicaid will also cover certain organ transplants.

To donate organs

1. Register with your state donor registry, if available. Designate your decision on your driver's license.
2. Talk to your family. To help your family understand and carry out your wishes, sit down with your loved ones and tell them about your decision to be an organ and tissue donor.

For more information, search “#DonateMyParts” on any social media.

There are those who feel that organ transplantation is a privilege of the elite, not always available to those on Medicaid. Some religions feel that it is a violation of the integrity of the body. A body is only available for organ donation after a medical declaration of brain death, and it will be kept on a respirator to maintain oxygen flow to the body until the “organ harvesting team” arrives to remove organs.



THE TESTIMONY OF EQUALITY (or equity) speaks to Friends' sense of justice. *Is it fair, just, to withhold organ donation? Every day in the US, 18 people die who are on an organ donation list; your donation may help as many as 8 individuals. Is it just to use a large amount of resources in the last days of your life? 28% of Medicare costs are spent on the last 6 months of life. Is it fair to sequester funds so that you can become Medicaid eligible? There are no easy or right answers to these questions, and we each need to consider them in the light of our commitment to justice.*

Personal Planner

Completing a Personal Planner is a last gift to your family, a single location that will answer so many of their questions in the first few days after death, plus it provides space to tell what is most important to you. Keep it with your other important papers and make sure they know where to find it.

Attach more sheets if necessary.

Name _____ Date _____

Address _____

Other places I have lived _____

Other names I have been known by _____

High School _____

College _____

Other degrees or training _____

Occupation(s) _____

Place(s) of employment _____

Married to _____

Date _____ Place _____ City _____

Additional marriages or partnerships _____

Children (names & spouses) _____

Grands and greats _____

Brothers and sisters (deceased?) _____

Clubs and organizations _____

Friends Meeting _____ Phone _____

Address _____ Year of membership _____

My lawyer _____ Phone _____

Address _____

Bank _____ Phone _____

Address _____

Account # _____ Safety deposit box # _____

Location of key _____

Other bank accounts _____

Location of personal bank records _____

Broker/Financial Planner _____ Phone _____

Address _____

Other assets, including property _____

Insurance policies _____

Location of important papers (will, deed, etc.) _____

Online Accounts (include passwords) _____

Where I want to be buried _____ Phone _____

Address _____

Is plot paid for? _____ I **have / have not** pre-paid my funeral (*circle one*)

Funeral home _____ Phone _____

Address _____

At my Memorial meeting please have (music, poetry, art, other significant objects or participants):

I would like my obituary in this/these papers _____

Please notify these people and organizations: _____

Location of my address book _____

Five last things

Whether you are dying or visiting someone who is, there are five last things that need to be said:

1. Please forgive me.
2. I forgive you.
3. Thank you.
4. I love you.
5. *(if you are the one dying)* It's ok, I'm ready to go...goodbye.

The people I need to ask forgiveness of: _____

The people I need to forgive: _____

The people I need to thank: _____

The people I need to say 'I love you' to: _____

...In fact, you might want to start now.

Ethical Will

An Ethical Will or the testament part of "last will and testament" is your opportunity to express your deepest convictions, not just the important events of your life, but also the moral and spiritual foundation of your life, the guiding principles for the decisions you've made and the joys and satisfactions you've had. You might share it with loved ones before or after your death.

Message to my loved ones: _____

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- fgcbookstore.org** – for pamphlet on memorial minutes and Quaker Memorial Meetings, Pendle Hill pamphlets
- undertakenwithlove.org** – for burials without a funeral director
- greenburialcouncil.org** – for a list of green burial cemeteries and funerals and a green burial provider consult
- sacreddying.org** – for information on vigiling
- beyondhospice.com** – which also has information on home burials and death midwives.
- funerals.org** – for details on not needing a funeral director
- organdonor.gov** – for your state's organ donation registry and forms
- naturalburialcompany.com** – for books and biodegradable coffins
- hankdunn.com**

Fill out and photo copy this page for extra wallet-size copies to keep with you at all times.
Cut out along the dotted line, and fold in thirds lengthwise to make it business-card size.

Health Care Proxy

Please print. Use the back for additional information.

I, _____

of (address) _____

(day phone) _____

(evening phone) _____

hereby appoint _____

of (address) _____

(day phone) _____

(evening phone) _____

as my health care agent to make all health care decisions for me if I become unable to decide for myself, including food and fluid decisions. This proxy will remain in effect indefinitely or until I revoke it.

Signature _____

Date _____

This proxy was signed in my presence.
The signer is known to me and appears to be of sound mind and to act of his/her own free will.

Witness 1 _____

Date _____

Witness 2 _____

Date _____

Health Care Proxy

Please print. Use the back for additional information.

I, _____

of (address) _____

(day phone) _____

(evening phone) _____

hereby appoint _____

of (address) _____

(day phone) _____

(evening phone) _____

as my health care agent to make all health care decisions for me if I become unable to decide for myself, including food and fluid decisions. This proxy will remain in effect indefinitely or until I revoke it.

Signature _____

Date _____

This proxy was signed in my presence.
The signer is known to me and appears to be of sound mind and to act of his/her own free will.

Witness 1 _____

Date _____

Witness 2 _____

Date _____



Please do not make unauthorized copies or electronically distribute this workbook. Your purchase helps to fund the work of the ARCH Program in New York Yearly Meeting – with the wider Quaker community – and beyond. We gladly offer workshops for groups and organizations on this and other aging related topics.

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