

SOME THOUGHTS ON END-OF-LIFE ISSUES WITH CATHY O'KEEFE
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Start by thinking about how you want your family to be after your death. I wanted mine to:

- Be competent to handle my affairs;
- Have the resources they need to do so without a huge hassle;
- Understand my general wishes for them as they grieve my death;
- Leave them with a feeling of being loved and cared for if I am able to be aware of them after death.

Let's take these one at a time:

1. Competent to handle my affairs. Think about who you want to ask to handle your finances and the division of your things after your death. Most people select a child or sibling. I recommend thinking about the difficulty that distance plays if the person you choose is very far away. Think, too, about any potential conflict that might be lying in wait and do what you can to head it off.
2. Have the resources that person needs to do so without a lot of hassle. If you don't have a will, you are making a huge mistake. A will can be a simple document. It doesn't contain a list of who gets your stuff. That can be done later in a "memorandum of understanding," a document that you make up and that can be changed over and over right up until death. The will, however, is a legal document that is essential in protecting your intentions about the larger issues regarding the division of things like real property, savings, stocks/bonds, etc. It identifies those who you want to legally recognize as your heirs, whether related to you or not. A good estate attorney can help, and it doesn't have to cost more than a thousand dollars to gather the will, power of attorney, medical proxy, and living will. Lawyers used to keep the original wills, but today your original wills are usually given to you, recognizable by a blue cover sheet. You can make copies, but those copies will NOT be recognized by any authority, so make sure you know where your original will is at all times, and if you have a representative you've selected to take care of your affairs, make sure that person knows where the original is.

I recommend compiling a binder of all that you'll need to be available to your representative. In that binder should be:

- The names of persons or agencies who need to be notified of your death in order of importance. Social Security Administration must be notified immediately, and though a funeral home often does that, I would follow up to make sure it was done. Pensions have to be stopped immediately, so the information about your SS number, pension account and holder of the pension needs to be in the very first page of the binder. The date you usually receive your SS check is important. You are entitled to get your final SS

check in the month of your death, but if the date you usually receive it is right at the end of the month, you could, if you don't notify them immediately, trigger another check, and then you've got a mess returning it. Let me say here that you should make sure now that the name on your SS card (and you should have that in your binder) matches the name on your driver's license. That's because banks use drivers' licenses as forms of identification. The death certificate uses the name as it appears on your Social Security Card. You can really mess things up if they don't match.

- Banks get notified of your death by Social Security. They freeze your account, and no one will have access to your funds until your representative produces documents showing their authority to act on your behalf plus a death certificate which can take weeks to obtain. (I once waited 5 months for my sister's death certificate because the funeral home botched the initial notification, and the probate court was so backed up due to short staffing that they couldn't produce them faster.) So, I recommend that someone you trust, or your representative, be on your account in some way that allows them access to it in case of your death. There are several ways to make that happen. The same is true for a safe deposit box. Have the person's name on it so he/she can retrieve your documents, especially the will, if it's in there. For people who own homes, the bills have to continue to be paid until everything is settled, so having access to enough funds to cover home maintenance for 6-12 months is ideal. My sister thought she had that all covered, but she didn't. Her account got locked, and I had to cover all her expenses, about \$17k, for 6 months after her death. Also, online banking makes it difficult for the representative to know information needed, so make sure that your representative is either on your account automatically after death or has all the information on your accounts to meet with the bank and transfer assets into an estate account.
- You will have to get an EIN number (very easy) on line to assign to the estate for tax purposes. If you are feeling overwhelmed, remember that the key here is selecting someone who is competent to handle your affairs, do these things I'm outlining, and keep great records in case they are needed.
- Some estates are simple, without real property, and no potential contestants of the will. Those can avoid going to probate in most states. So, make sure that deeds are transferred prior to death if you want to avoid probate. If you think there will be people contesting the will, you probably should go through probate court for that added protection. It isn't cheap, but it may keep you sane. If you have to get an attorney to help with the estate, make sure you get clear information about the payment. Paralegals do most of the work, and I've seen the fees be HUGE because the paralegal AND the lawyer are both charging you for the same things. If you have to see a lawyer, go prepared

with a concise, correct list of all the heirs, their names, addresses, birthdates, phone numbers and email addresses, or you will pay to have them to type up what you easily could provide. You are looking at \$350 an hour for many of these attorneys.

- Disposition of the body – The most important point is to convey your wishes to your representative but realize that the best laid plans often get stymied. For example, if you line up anatomical donation, that could fall through if the time of death isn't clear, if the medical institution doesn't need your body or won't take it for some last-minute reason. Always have a backup letter saying what your wishes are should anatomical donation or some other first choice, not be possible. A signed permission to cremate is a recommended backup document for your binder. If you don't have that, signatures have to be obtained by the next of kin. Be wary, too, of high-cost funeral plans. Families have good intentions, but make sure that the person has the resources to cover these expenses right after death in addition to all the other costs that need attention. I'm not a fan of prepaid plans because so much can happen to change the circumstances of death plus the financial needs, but I understand why people have them. Make sure that any burial in a cemetery is covered with documentation of plot ownership and a plan for a marker if needed. In most states even a box of cremated ashes must be placed inside a concrete vault prior to burial. Buy one directly from a company that makes headstones. Don't buy it from the cemetery or funeral home, or you will be paying significantly more for it. If the ashes will be dispersed, check with State regulations as there are restrictions about ashes in rivers, lakes, creeks, and close to shorelines. Be aware of new trends in green burials that are emerging across the nation.
3. Have conversations well before you are close to death about your "stuff." State plainly your intent in distributing your assets. For some, a concern is fairness; for others it's helping those less able to help themselves. For some, it's charity; for others it's helping grandkids with resources for the future. I strongly advise you to either write, record, or have discussions with your heirs about your desires. No one is entitled to your things/money. Make sure they understand that. And if you are worried about jealousy, you're better off giving things prior to your death so that can be seen and worked through. There may well be hidden assumptions that your heirs have or desires for certain items. Decide in advance how you are going to handle that. Some lay it all out or give most of it away in advance; some have the heirs pull numbers and then take turns choosing from a list of equally valued items. If you sense that there may be real trouble, you might be better off getting someone outside the family who doesn't have a stake in the outcome to manage your estate. We are all going to die, and we can't take it with us. And guess what? Today's young people often don't want the stuff we have! My kids refer to my antiques as "the brown furniture." So, lighten up and let stuff go if your heirs aren't interested.

If you are going to be cared for by one child, and that child is more burdened by that reality, I recommend that you let the others know how you feel about your care, who should help, how they can help, and how that effort should be rewarded. But be sure to lean on a competent heir, friend, or professional to help you, or there could be more trouble than you'd ever want after your death.

4. On the topic of end of life care, let your loved ones know what benchmarks are key to you in deciding medical options. Your medical proxy will need to make decisions on your behalf should you not be able to speak for yourself. Anything that you can share with them that helps them know how far you want them to go on life extending measures would be helpful. I've already told my kids that if I get to the point where I'm very confused from dementia, stop all the usual drugs I take daily to maintain my health. Don't do anything life-saving if I get sepsis, and allow natural death if at all possible. There is a book called *It's okay to die* and an interview with the author on YouTube by the End of Life University that has guidelines for advanced directives that are based on benchmarks like the ones I've described.
5. Clarify all the options about where you could die (home, hospital, in-patient hospice) and answer these questions or defer to others: Who will be my primary caregiver or coordinator of my care? What do I want during the dying process – a quiet venue with few or no visitors? A social venue where family and friends can come and go? Do I prefer the placement of my bed in a bedroom or in a larger space like a den or living room? Do I want music to be part of my end-of-life experience? If so, what kind of music do I want? Could I or a friend/family member make a playlist of music that I will find soothing, encouraging, spiritually comforting? Do I want the natural light of a window close to the bed where I can look outside? Do I want essential oils/fragrances/incense? Do I want ambient/candle, low, or normal lighting? Are there any particular tastes that I might enjoy that could be put on my tongue when I can no longer eat? Is there a clergy person who would be my preference for end-of-life prayers? Is there any particular person(s) who I want included/not present around at the time of my death? Are there any prayers or poems or songs that I'd like around the time of my death (favorites or ones that I've composed)? Do I want a pet included in my end-of-life experience? Do I want my children and grandchildren to do all they can to get to my bedside before I die? Be there at the time of my death? Wait for notification until after death? Attend my funeral/memorial service? Do their own memorial convenient to where they live? Have a service quickly? Wait to have a service weeks or months later? Not have a service at all? Do I want to set aside funds to help with travel expenses? Publish an obituary? Share stories at a wake formally/informally? Do I want family and friends to create a photo or video montage to share?
6. Understand your general wishes for them as they grieve your death – I recommend letters, video, or discussions with your heirs to help them bridge the impact of your

death. It's very easy to use Zoom to create videos for your family. All you have to do is open your Zoom meeting, hit "record," hit stop when you finish and answer the prompt indicating if you want the recording stored on your desktop or in the cloud (I use desktop) and then enjoy telling your kids, grandkids, spouse, friends, etc. any number of things. When you are finished, the digital file will upload to your desktop or cloud right then. Here are some great topics:

Stories about your life; Stories about the people who will be watching the videos later like memories of the birth or early years of each child/grandchild; genealogy information that you know; funny stories of your family; how you experienced historic events during your lifetime; your core beliefs and values; your hopes for the future; your commitment for continuing your relationship after death. How you have coped with loss and what you have learned that might be of help; your wishes for your memorial service/funeral and disposition of ashes or body.

7. Leave them with a feeling of being loved – I'm a big fan of making videos for each child, grandchild, close friend, etc. , saying their name, telling them how much I love them and assuring them of my continuing love in the years ahead. I like choosing some object or song as a special sign between us. I sang on videos to my grandkids little lullabies that I sang to them when I rocked them as babies. If you have grandkids, you can get some storybooks, maybe some of the favorites of theirs and read them aloud on the video. Then, they can listen to you read to them anytime they want. If you are making a video for a teen, I recommend telling him/her that there is nothing they could do during those tumultuous years of adolescence to disappoint you or make you turn away. Let them know that you will be with them, guiding them in any way you can toward their best choices.
8. If you have photographs that you want to share with multiple children (maybe of ancestors or of key events in life), take pictures of them with your phone and send them to all the family members who might be interested. Then, if they want, they can get them made into prints. Do your loved ones a favor – if you have photos of ancestors, label the back indicating who is in the photo and the context in which it was taken. Add the date if you know it.
9. If you are what is called a "Perennialist," that is someone who believes that life goes on after death, talk to your loved ones about how you envision your relationship with them after you die. Dying doesn't end a relationship, even if there is nothing after we die. The people who survive us take memories of you with them and incorporate those memories into the meaning of their own lives. So, be thoughtful about how you want to be remembered, and talk about that with your family and friends. If you sense that your relationship includes wounds, ask for understanding. Maybe a good conversation will, quickly or over time, lead to forgiveness and a healing of any hurt you or they have caused.

10. How we die: There is a video on YouTube called "*The Dying Process*" by a nurse, Barbara Karnes, who has worked hospice for decades. I always encourage people to listen to it way before death is on the radar. I think you can hear it more clearly without the fear of something imminent looming. She's a great nurse, very down to Earth, and explains the dying process so well. Just Google it. You need to know that hospice care has evolved over the past 30 years. It started as a mostly volunteer service via non-profit or religious institutions. Then it morphed into a for-profit industry once Medicare covered it as a benefit. The guidelines for qualifying and remaining on hospice are quite strict, and many agencies have been fined by the Centers for Medicare and Medicaid Services (CMS) for keeping people on hospice too long. Some hospices have the option of an in-patient or respite center; others are strictly supportive of death at home. Some contract with nursing homes to provide hospice services in that setting. Understand that being on hospice does NOT mean that someone will be with you at bedside either in the time leading up to death or during the active dying process. That supportive role is still up to family, friends, or paid caregivers at home or in nursing homes.

11. If you have died at home, your caregiver will call hospice, and they will send out a nurse who declares the time of death and fills out the paperwork needed. The nurse will then notify the mortuary you have chosen to remove your body. I recommend that your family let the nurse know up front that they want time with your body before it is removed. Many families want to wash and prepare the body, have a ritual or prayers/sharing at the bedside. Remove any valuables like jewelry should these be keepsakes for the family. Time may be needed for some family members to get to the bedside. It could be several hours before the body is ready to be moved. The nurse can even delay coming to the home to give the family extra time. But once the nurse arrives, a process is put in motion, and because the nurse may have other patients to see, family time can be shortened. So, take your time contacting the nurse. Patients who are on hospice with advanced directives that indicate "allow natural death" or "do not resuscitate" are directed NOT to call 911. The proper contact at that time is the hospice nurse. 911 calls necessitate that all measures possible be taken to resuscitate a patient, a measure that is counter to the purpose of hospice.

12. I recommend that family members at the bedside of the person who has died think about where they want to be when the mortuary comes to remove the body. For many, that's not the last image they want of the person they loved. For others, accompanying the body out to the mortuary's van is an honor. Give people the choice to leave the area and perhaps go sit on a porch or in some other spot where the removal isn't seen; Or, give the caregiver the opportunity to place the blanket over the gurney and accompany it out of the home. If death occurs in an in-patient hospice, hospital, or nursing home, the mortuary and nursing staff will handle the retrieval of the body.

13. The cost of preparation for viewing, the casket, funeral accompaniment by mortuary staff, a procession, burial, and monument can amount easily to up to \$15,000. Low cost cremation can be arranged directly with a crematory. The family can pick up the ashes, and there are no additional roles for a mortuary to play.
14. Cremation allows a family to have plenty of time to plan a memorial service. The traditional wake and funeral is usually done within a week or two of death. Jewish and Muslim traditions require burial quickly. There are no right or wrong ways to handle end of life disposition of the body or burial. Today, there are more options than ever for an end of life celebration.
15. Consider using a doula or becoming one yourself! Ideally, we should all become more comfortable with the dying process. Training to become a doula is a practical way to prepare for your own death or for the death of family members for whom you might be the caregiver. On line and in person training is available via INELDA or other organizations. The point is to be more knowledgeable and prepared for something that surely we all will be addressing at some point.

Resources and bibliography:

It's Okay to Die by Monica Williams-Murphy. She is an ER physician who has seen more than her fair share of mix-ups at the end of life. This book contains her advice for being prepared for the unexpected and what families should know about our wishes.

Caring for the Dying: The Doula Approach to a Meaningful Death by Henry Fersko-Weiss, Founder of INELDA, the International End of Life Doual Association

Advice for Future Corpses (and those who love them): A Practical Perspective on Death and Dying by Sallie Tisdale. The book is a direct and honest look at dying with lots of advice on how to live and die.

End-of-life University can be Googled, and all kinds of great podcasts and resources are available via the youtube link. I recommend anything by Barbara Karnes (BKbooks.com). Hospices often keep her set of booklets on hand for families.