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Help Protect the Heart of Those You Love

By **Regina V. Cates**

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Lying alongside the Mississippi River, La Crosse is the largest city on Wisconsin's western border. With an estimated population of around 52,500, the city is a regional center for technology and medicine. But, La Crosse is most famous for something much rarer - being the town where almost everyone talks about death. In a very healthy way.



Long-time residents of La Crosse, George Phillips has his death planned out. His wife Betty has also planned hers. They have filled out an advance health care directive, outlining how they want to die.

Their neighbors across the street have filled out the same paperwork, as has the family next door. In fact, in La Crosse, Wisconsin, you're unusual if you don't have a plan for your death. Some 96 percent of people who pass away in La Crosse have an advance health care directive (a living will) or similar documentation. But nationwide, in the United States, only about 30 percent of adults have this kind of document.

In this community, talking about death is a comfortable conversation. In fact neighbors talk about who on the block hasn't filled out their advance health care directive. It's become an easy dialogue because of one kind and caring man.

Bud Hammes is a medical ethicist at the local hospital, Gunderson Health System. For years, he

was called when someone's dad had a stroke, was in a coma and on life-support. Bud would sit with the family and try to help them figure out what to do next. And every time, he says, the discussion was excruciating.

"The moral distress these families were suffering was palpable," he says. "You could feel it in the room." Most of the time, Bud says, they'd be talking about a patient who had been sick for years. Why not have the conversation earlier?

So Bud started training nurses to ask people ahead of time, if they wanted to fill out an advanced health care directive. It took time, but the idea caught on and spread throughout the entire community.

Nurses ask patients questions like: "If you reach a point where treatments will extend your life by a few months but the side effects are pretty serious, would you want doctors to stop, or continue to do all that could be done?"

Many patients said: Stop. And stopping, of course, is less expensive than continuing treatment. But, reducing health care costs wasn't the reason La Crosse has its advance health care directive program.

Bud Hammes was simply trying to help patients be prepared for the end of life and to help prevent family members from suffering needlessly. *Heard on Morning Edition of National Public Radio and transcribed by Chana Joffe-Walt*

When I first heard the story of La Crosse, Wisconsin I wanted to shout for joy from the highest mountain at the wisdom of our being prepared to die. I was deeply moved by what the vast majority of people in La Crosse choose to do. Through a very hard personal experience I know the importance of conveying one's desire for how we want to deal with the end of our life. I know making these hard decisions beforehand is one of the most valuable gifts of love we give to the people we care for. I learned this valuable lesson by experiencing the additional suffering caused when a loved one

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does not take time to deal with the very real and necessary business side of love.

My beloved aunt passed away at the age of 92. The entire year before her death she suffered needlessly due to her unwillingness to allow physicians to amputate a gangrened toe. As a result the infection entered her blood stream and slowly spread throughout her body. She was wracked with pain from sepsis; the ultimate cause of her death.

As we sat by her side the last days of her life, she went in and out of consciousness. My mother, cousin and I were by her side when she passed away.

Of course her passing was hard. It's painful to say goodbye to those we love no matter how young or old they are. Yet, the pain of her death was intensified ten-fold because my aunt did not create an advance health care directive. She did not sign the forms required to give my mom, her only remaining sibling, end of life instructions.

During the year before her death, on three separate occasions, the family sent attorneys to her home with all the necessary paperwork. Two of those attorneys were family members and people she knew and trusted. My aunt was charming each time an attorney, family member or not, arrived. She offered tea and pleasant conversation. But she continued to refuse to sign the documents.

Finally something or someone changed her mind. One day she went to her bank with documents in hand. She was ready to sign in front of a notary to ensure the paperwork was legal. But the notary was not at the bank the day she decided to go and she did not feel well enough to find another.

The very next day my aunt slipped into unconsciousness. She was rushed to the hospital leaving the documents unsigned on her living room table.

I was with my mother when she had to make the agonizing decision not to resuscitate my aunt. Mom was forced, against what she would have preferred, to make the choice to take no further action, not knowing if her decision was what my aunt would have wanted or not.

Although my aunt did not intend to compound our suffering over her death, she did. By refusing to get her end of life affairs in order before she got so sick she further broke our hearts.

Now my aunt was gone and the health care directive was no longer an issue. Yet, the heartbreak continued to magnify because my aunt left no last will and testament. Without a will our family had no idea what my aunt wanted to do with her home and things. With the exception of her much-loved Dalmatian dog, Marshall, probate attorneys and the court would decide what would happen with the money, house and possessions my aunt had.

Again, we were powerless to prevent the ongoing heartbreak. My aunt was a very smart woman. But she did not do what she could, in order to ensure those she loved would not suffer more than necessary after her death. It's not like my aunt did not have firsthand experience what a mess is left when a loved one passes away without having the necessary legal documents.

I was twenty-seven years old when my cousin, Kathy, my aunt's only child was killed in a horrible car wreck. At twenty-nine she did not have a will. My aunt and uncle were faced with a similar situation that we were with my aunt's estate.

I learned from my cousin's death how important it is to do whatever I can to prevent the needless suffering of those I leave behind. I have a last will and testament, an advance health care directive, a durable power of attorney, and other documents and instructions. I completed these very soon after my cousin's death. And, I keep these documents updated on a regular basis.

I intentionally made dealing with the business side of love a top priority. The horrible tragedy of my cousin's death taught me I am not promised any length of time in life. Therefore, I took the necessary action to do exactly what needed to be done. I did so motivated by LOVE for the people I care for.

My aunt did not learn the same lesson from her daughter's death. The family thinks maybe my aunt was afraid. If she faced her own mortality it would hasten her death. This illogical fear prevented my aunt from moving forward to complete the necessary legal documents. Avoiding the business

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side of love caused my aunt stress and uncertainty. Not having the documents prepared did not prevent her death. But the lack of attention to engaging in healthy conversations about her death resulted in added grief and unnecessary expense for those left behind.

There is a business side to loving you and I cannot ignore because we don't want to talk about it or we don't want to face our own mortality. To truly love others is to do everything within our power to prevent what suffering we can beforehand. We don't allow ourselves to pretend death or a devastating illness won't happen to us. Yes, someday, we will pass away. Being legally prepared to pass away has nothing to do with when we actually die.

We do not know when we will leave life, but we know moving on at some point is inevitable. Consequently, one huge responsibility in loving others is to tend to the business side of love to prevent those we care for uncalled-for misery.

I don't know the legal requirements for the country in which you live, so please do your own research to get your affairs in order. However, I am familiar with what steps you and I can take as residents of the United States.

The first action necessary to protect the heart of those you love is to complete an advance health care directive, what is called a living will. This document gives someone you entirely trust the medical power of attorney to carry out your wishes about treatment at the end of life.

For example in the advance health care directive I have in place, my agent (spouse) is authorized to act for me in all matters relating to my health care. My agent's powers include, but are not limited to:

- Full power to consent, refuse consent, or withdraw consent to all medical, surgical, hospital and related health care treatments and procedures on my behalf, according to my wishes as stated in the document, or as stated in a separate living will, or other similar type document, or as expressed to my agent by me;
- Full power to make decisions on whether to provide, withhold, or withdraw artificial nutrition

and hydration on my behalf, according to my wishes as stated in the document, or as stated in a separate living will, health care directive, or other similar type document, or as expressed to my agent by me;

- Full power to review and receive any information regarding my physical or mental health, including medical and hospital records, in accordance with the Health Insurance Portability and Accountability Act of 1996, 42 USC 1320d ("HIPAA"), and the American Recovery and Reinvestment Act of 2009 ("ARRA");
- Full power to sign any releases in order to obtain this information;
- Full power to sign any documents required to request, withdraw, or refuse treatment or to be released or transferred to another medical facility.

Since this is only an advance care directive for health decisions, my agent does not, through this document, have authority to act for any other purpose unrelated to my health care. And I am the one who made each decision required within the advance health care directive indicating what I desire happen under every situation listed. Such as, not wanting a feeding tube installed or to be resuscitated; among several other decisions.

My very smart aunt did not spell out her wishes. So, my mother, her closest living relative, had to make all the medical decisions.

Like the vast majority of citizens of La Crosse, Wisconsin have learned, an advance health care directive is one of the most important documents for us to have in place. Your husband, wife, partner and doctor may clearly know your wishes, but your parents can block them from carrying them out if you do not have an advance health care directive in place.

The second loving legal action to take is for you to write a last will and testament. This is a document stating your final wishes. You can write a will yourself, or you can hire an attorney to write one for you. If you write one yourself, you'll want to find a good last will and testament template, available on the internet, to guide you.

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Primarily a will is used to leave instructions about what should happen to your property after you pass away. This includes naming guardians for your minor children and their property and providing for your pets.

For children with disabilities consult a professional who can guide you through the confusing maze of Medicaid and Medicare rules. If you leave everything to a disabled child he or she will not be eligible for aid. Your disabled child will have to use up the entire estate before they qualify for aid. So be sure you name a trustworthy and impeccable guardian for a child with a disability. For this situation please consult an attorney.

Similar to an advance health care directive, you use a will to name an executor. This is someone you know who is honest, impartial and diligent. The executor must be someone who will act with scrupulous good faith and reliability on your behalf to protect your assets until all debts, and taxes have been paid, and what is left from your estate is transferred to the people you name in the will to receive your assets. Your will is read by the executor after your death. And, the executor makes sure your final wishes are indeed carried out.

Creating a will is not difficult, or costly, nor is it a process filled with lots of legal requirements. Basically in the U.S. there are four steps to creating a last will and testament.

First, you must know what property you have and what it means to leave what you have to someone after your death. In legal terms it is called having “capacity” or being of “sound mind.”

Second, you create the will naming the beneficiaries for your property (home, car, pets, land, money, things). Third and fourth, you sign the last will and testament in the presence of two people who also sign as witnesses. For this you want to get two people who are impartial like a co-worker, your pastor, or someone who is not related to you or a close friend.

While at the time of this writing no state in the U.S. requires a last will and testament to be notarized, it makes the will easier to get through probate after your death when you use a notary. So get your last will and testament notarized. And, avoid a

handwritten will as they are much more susceptible to challenge after your death.

In addition to completing an advance health care directive and a last will and testament, there are several more actions you can take right now to prevent unnecessary pain and suffering for your loved ones. Decide who is going to pay your bills, deposit checks, and manage your personal financial affairs and your business if you have one, should you become incapacitated or pass away.

This can be done by giving someone a durable power of attorney. This document is different than your advance health care directive or your will. And just as you would for your advance health care directive, choose a trustworthy and honest person to manage your affairs should you become sick and unable to do this for yourself.

A durable power of attorney allows you to choose what your personal representative, or attorney-in-fact, will be responsible for by designating certain powers to them. The powers you can grant your attorney-in-fact include, but are not limited to:

Real Estate: To buy, sell, rent, or otherwise manage residential, commercial, and personal real estate.

Business: To invest, trade, and manage any and all business transactions and decisions, as well as handle any claim or litigation matters.

Finance: To control banking, tax, and government and retirement transactions, as well as living trust and estate decisions. Financial powers also allows your representative to control personal insurance policies and to continue donating to any charities in your stead.

Family: To purchase gifts, employ professionals, and to buy, sell or trade any of your personal property.

General Authority: This grants your personal attorney the authority to make any decisions that you would be able to if you were personally present.

Like an advance health care directive and last will and testament, the form to legally name a durable power of attorney is also available online. Be sure to add the person you choose to act as durable power

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of attorney to your bank accounts. To manage your financial affairs he or she must be able to write checks on your behalf. Most likely your bank will require your durable power of attorney to be officially added in order to sign on your account(s).

Another important action to take in advance is to plan your funeral or memorial service and how you want your body disposed of. Please be love in action and do not leave these type decisions to those who are left behind. It's hard enough for your loved ones to go through your death without the additional stress of trying to figure out what you want.

The only instruction my aunt left about her funeral was which funeral home she wanted to use. It's the most expensive in Houston, Texas. After her death my mom, cousin and I had to make all the decisions.

We had to drive from the hospital where she just passed away directly to the funeral home. We did not have time to gather our thoughts in order to make the best decisions possible. We were ushered into a very cold room with caskets each more expensive than the one before.

Then there were countless other decisions to be made on the spur of the moment. About flowers, photos, the funeral program, burial, clothes my aunt would wear. It seemed the decisions we had to make immediately were endless. And each decision had a cost associated with it.

In the end my mom and dad had to pay almost \$40,000 for the funeral and burial. Yes, you read correctly. My aunt's casket, head stone, and everything else for her funeral totaled almost \$40,000. And we did our very best to keep costs down.

Remember this end of life service is a business for those who operate funeral homes. So the entire process would have been so much easier, less costly and less overwhelming if my aunt had made prior arrangements or had a burial insurance policy in place.

Please don't leave it to your family to figure out what you want. Please do not leave them with a huge expense.

Do what you can now to let your loved ones know what you want done with your body. If you are financially able to do so, prepay for your funeral

or cremation. At the very least think about the financial burden you will leave for this costly end of life service. Prepare now to cover this expense.

I recently pre-paid for my cremation and burial at sea through the Neptune Society. While I do not have children, I do have family and many friends. I certainly do not want any of them stuck with the responsibility of deciding what I want when I pass away. I also do not want anyone stuck with having to pay for this expense which is my debt to assume.

Now, with a simple phone call to Neptune Society, no matter where I am in the world, my cremation and the return of my ashes to my home is already arranged. My letter of instruction outlines what I'd like for a service, leaving nothing for my durable power of attorney to do other than write a check, from my account, to cover my memorial.

Taking the necessary actions to prevent avoidable suffering for your loved ones requires you ask the hard question of what you want done with your body. Do you want to donate your life-saving organs to someone in need? If so, carry an organ donor card in your wallet like I do. Keep a copy with your important papers.

Do you want to be buried or to be cremated? Or do you want to donate your body to science?

In addition to the above vital decisions, another step to consider as an act of love is to purchase a Term Life Insurance policy to make sure your spouse, partner, and children have the needed financial support after you pass away. Think about how much your loved ones would need to pay off a mortgage, car note, outstanding credit cards, and funeral and burial expenses. Also consider future education expenses for children. To help with the financial burden of your death, secure a Term Life policy with a reputable company. I have one which provides me great peace of mind. It's a small monthly price to pay should your family need this type of financial support.

Also, consider long-term care insurance. I know it's an uncomfortable conversation but it is a necessary one to ensure your loved ones have the least stress possible. It's responsible to start the planning process sooner than later.

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The Parent Care Conversation, a book by Dan Taylor, offers detailed suggestions on how to talk about this issue with your parents and your children. I strongly suggest consulting with an expert in long-term care insurance. You want to make certain the policy you choose now will indeed pay for your care in the future should you need this type assistance.

In addition to everything I've outlined above you can further help loved ones by keeping a folder or safe deposit box with these twenty-five important papers in one place. Suggested by the *Wall Street Journal* they are:

1. Marriage license
2. Divorce papers
3. Personal and family medical history
4. Durable power of attorney
5. Authorization to release health care information
6. Living will (health-care directive)
7. Do-not-resuscitate order
8. Housing, land, and cemetery deeds
9. Escrow mortgage amounts
10. Proof of loans made and debts owed
11. Vehicle titles
12. Stock certificates, savings bonds, and brokerage accounts
13. Partnership and corporate operating agreements
14. Tax returns
15. Life insurance policies
16. IRAs
17. 401(k) accounts
18. Pension documents
19. Annuity contracts
20. List of bank accounts
21. List of user names and passwords
22. List of safe deposit box(es) and location of key(s)
23. Will
24. Letter of instruction
25. Trust documents

Please create a password protected document with a list of the login and password information for all your bank accounts, credit cards and automatic bank draft accounts. Make certain to include Netflix, Apple, utilities, everything that would need to be turned off or cancelled upon your death. Also, include the location of safe deposit boxes and where their keys are kept. Provide this document to your durable power of attorney along with the password needed to access it. Also give him or her a letter of instruction about your wishes for a funeral or life-celebration.

Although the above seems like a lot to do, I assure you creating the necessary documents and gathering this vital information is a very small investment compared to the huge relief it will be for those you love. You and I cannot prevent the pain our loved ones will feel when we pass away. But we sure can take every action now to make certain their pain of loss is not compounded by our lack of being prepared.

Today, right now, begin taking action to help protect the heart of the people you care for. Check the laws in your state and then create an advance health care directive. Write a last will and testament. Complete a durable power of attorney. Have all three notarized.

Decide what you want done with your body. Check into a Term Life Insurance policy. Plan and prepay for your funeral or cremation. Create a letter of instruction outlining specific instructions for what you want as a memorial service. Make the list and put in one safe place all the important information suggested by the *Wall Street Journal*. Make sure your durable power of attorney knows the location of these documents.

You will sleep better knowing you have done everything you can beforehand to prevent your loved ones unnecessary suffering. And, I guarantee your loved ones will truly appreciate you caring enough about them to have the business side of love in order as a last gift of love to them.

Regina