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ADVANCE DIRECTIVES

Why Fill One Out?

What is an advance directive (living will)?

It's a document (or sometimes a couple of documents) where you make it clear what you'd like to happen with your medical care if you ever become so sick you're not able to make those decisions for yourself.

There's a place to name someone to make those decisions for you, if that time ever comes.



Why would someone would fill one out?

An advance directive lets you plan ahead for your future health needs in case you don't have that chance later on. This helps your loved ones know what you'd want in a difficult situation, which can really help them emotionally.

An advance directive is a gift to your family and loved ones.

Here's an example: Jane gets in an accident and is in a coma. She doesn't have an advance directive, and she never had a conversation with her family about what she'd want in this type of situation. They all have different ideas about what's best to do. Even though everyone only wants to help, they're confused and feel guilty they might not do what Jane would've wanted. Instead of spending time together and with Jane, they fight a lot about what's best.

When someone's not well

There can be disagreement between loved ones about what to do for the sick or injured person. But when that person can't communicate or guide their loved ones through written wishes, it creates even more stress. It's different for everyone, and only you know what your family is like. But no one can know for sure how people will act in a crisis. So setting things out in advance can be a big relief for everyone involved, if and when the time comes. It's like leaving a guide book for your loved ones.

Who makes decisions for me?

If someone isn't named to make decisions, then legally, doctors have to follow their state's laws about which family member should make the decisions. So you may end up with someone you do NOT want making decisions for you. For example, if you're separated but technically still married, there's a good chance your husband or wife could end up making decisions for you. It's also important to keep in mind, whoever you DO choose will only make decisions if you cannot communicate your wishes yourself anymore.



Some people worry getting things down on paper might jinx them.

Just because you write down your wishes, of course it doesn't mean you're giving up on living a long and healthy life. Filling one out won't get you closer to the end. Talking or writing about the end of life can feel strange, but if something happens to you, you need something or someone to speak for you. For example, many people say they

don't want to be on something like a breathing machine or anything that has to be turned on to keep them alive. But if they don't write that down, they could still be put on one.

Does an advance directive mean I'll get less care than I want?

It actually gives you more control over your care. If you complete an advance directive, it can help make sure you get the treatment you want, especially if you name someone who knows and can carry out your wishes. You will determine what you want, whether that means listing treatments you don't want or putting down you'd like everything done to try and keep you alive. Your doctor will do his or her best to follow those wishes. In fact, if you want to have specific medical instructions for a condition you have, like for lung or heart disease, you can fill out a more detailed form with your doctor. That's the great thing about advance directives — you can make them as detailed or as general as you want. There's not one right way to do it.

Are advance directives are set in stone?

Again, that's not true at all. They're a document you can change whenever you want, just like a financial will. In fact, it's a great idea to take a look at your advance directives after major life or health changes, like getting married or having a child. It only takes a minute. And you don't even need a lawyer. Of course, you don't have to. If everything is still as you want it, you can leave it alone.



What if I don't feel like I need an advance directive now?

You're not alone. Especially if you're healthy and independent, it can seem like an advance directive is a little bit much. But you never know what can happen. That doesn't mean you need to live in fear. It's just good to be prepared in case something happens, even if it feels like that kind of thing would never happen to you. Hopefully, it won't.

What if I already chose my decision-maker?

Some people may have decided who they want to make decisions for them, but they haven't talked it through or written it down yet. They may think, "Oh, my decision-maker knows what I want. I don't need to talk to them about it or write it down." But having the conversation about what you would want is one of the most important steps in planning for the future. Your person needs to know you want them to officially be your decision-maker if you can't speak for yourself. Next, there's the step of writing it down. This is so important because unless you write it down, the medical team has to ask the person the state tells them to.

Talking about death

Even just hearing the word can make people uncomfortable — and that's very natural. It's a tough topic most of us stay away from. But that can't be an excuse to avoid planning for the future. If anything, you can use it as a bonding moment when you speak to your loved ones. You can start the conversation with something like this: "I know none of us wants to think about not being around any more. But I want to help you be prepared if anything should happen to me because I love you."

Some of your family may not want to talk about it. That's OK. Setting up advance directives and getting everyone on board isn't always a quick and easy thing. Sometimes it takes a few conversations, and those can happen over time. It just depends on who's involved.



Start the conversation

It's so important to start the conversation, especially with the person you want to speak for you. Because only you know what's best for you. If there are things you definitely do or don't want, it's important to get that down in writing and let your decision-maker know. Then, your family and friends are given the gift of knowing exactly what you'd want.

What's In Advance Directives?

What's involved in creating an advance directive?

Each state has their own rules. Depending on where you live, you might have one or more documents. The names for all the pieces of advance directives are different state to state. Names like:

- Living will
- **Proxy or agent**
- **Durable power of attorney**
- **Healthcare surrogate**

The names aren't really important. What matters is you get the information you want down in paperwork accepted by your state. If you want, you can have just your wishes, just a decision-maker, or both written down.

Where you can get the advance directives forms

There's a free national website you can go to, if you want to find the exact forms for your state:

<http://www.caringinfo.org>. Just make sure to click on the link called Download Your State Specific Advance Directive. There are other sites you can look at, too. Or you can ask your doctor, lawyer, hospital chaplain, or social worker about them.



Healthcare decision-maker

Remember, your decision-maker is the person who will make medical decisions for you — but **ONLY** if you're unable to make them yourself. This person should be able to make decisions for you that reflect what **YOU** would want — not what they want. Think about who could do that for you. Sometimes it's not the person you'd automatically think of.

Who to choose

Lots of people have one person in charge of their finances and someone else in charge of their medical decisions. Some people have the same person for everything. It all depends on who you feel comfortable with, and who you trust to carry out your wishes. Keep in mind, it doesn't have to be a family member, if you'd prefer someone else.

Talk with the person you choose.

First, let them know you'd like them to be your decision-maker if that time ever comes, and ask them if they'd consider it. Can you imagine how surprised they'd feel if the time came and a doctor said, "OK, you're in charge. What should we do?"

If they agree, then have a conversation about what you'd want. I know that's usually easier said than done, but remind them you care about them and want any difficult situations to be as easy as possible for them. Sometimes it helps to use other people or famous situations as an example. (Saying things like, "you remember that girl in Florida?" and taking it from there can make it easier for some people.) Make sure your



decision-maker really understands what you would and would not want.

Lastly, give them a copy of your advance directive, including the paperwork that shows they're your decision-maker. It's also good to let others know who you've chosen, especially in your family. This will make things easier if the time ever comes for that person to step in.

Think about extra measures.

Another part of advance directives is thinking about whether you'd want a medical team to do everything possible to keep you alive, or if you'd prefer to pass away without all the extra measures taken. (Extra measures can be things like **CPR**.) This can be a little uncomfortable to think about, but it can be as general as, "when it's my time, I want to be at home with family."

CPR

CPR is when someone pushes on your chest to try and keep your heart beating and your blood moving when your heart stops. You might have seen this on TV when the paramedics come in and save the day. They pump hard on someone's chest, put those square things on them and yell "CLEAR," and the person comes back to life, sitting up and hugging the person who saved them. It looks pretty impressive. For some people, especially if they're healthy otherwise, it can work well.

But for most people, especially if they're older or sick already, CPR rarely works to save them. It can be pretty painful. What they don't show you on TV is CPR often cracks rib bones and damages internal organs, even when it's done right. If they use the square things (paddles), those will send electricity into the person's body to try and shock their heart back into working. This can all be very hard on the body.



For loved ones who see it happen, it can be VERY scary. So some people decide it's not something they would want. It can be different for everyone. You can ask your doctor what it might be like for you.

DNR order

You may have heard of a form called a **Do Not Resuscitate** (DNR). Sometimes it's also called an **Allow Natural Death** (AND) order. This is a doctor's medical order that says if your heart stops beating and you stop breathing, you do not want anyone to try and bring you back with CPR or with a breathing machine. Usually, it's for someone nearing the end of their life.

Ventilator

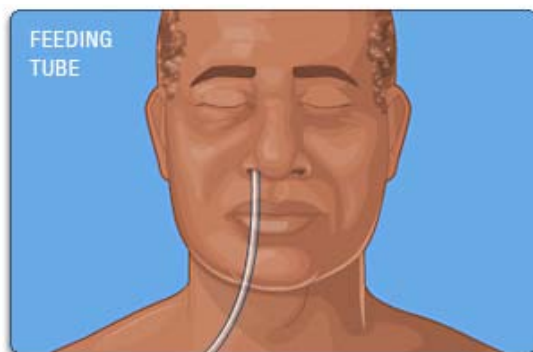
Another thing to think about, especially if you have lung problems, is whether or not you'd want to be on a **ventilator** if you ever have serious trouble breathing. This is the breathing machine people get put on when they get **intubated** (when a tube is placed down their throat to help them breathe). When their lungs aren't strong enough, the machine takes over their job and moves air in and out of their body.

This may be used for just a few hours or for weeks, months, or even years. For people with serious lung problems, it's possible that once they go on a ventilator, they'll be on it for the rest of their life. You may want to think about situations where you would or wouldn't want to be intubated and what you'd want to get from this treatment. For

example, if someone survives CPR, they're sent to the intensive care unit (ICU) and are put on a ventilator to let their body heal for a while.

Feeding tube

If you're sick or injured, you could have a tube giving you a chemical mixture of nutrients for a short time (like a few days) or a long time (like months or years). If it's for a little while, you could have a tube that goes through your nose into your stomach. Or, if it's for a long time, a tube goes through a small hole in your belly. Some people decide they never want a tube. Others decide they're OK with being on it if it's helping them get better, and some people fall in the middle. Think about what it might be for you.



Other medical procedures

You can leave more specific instructions on other medical procedures, if you want. You can do that with your doctor. Just talk to him or her about it if you're interested. But, like I said before, you don't have to include a decision about any of these things as part of your advance directive.

Choosing to do everything

There are people who choose to have everything done to try and keep them alive, no matter what. That's OK. After all, this is your body and your life. The choice is completely up to you.

Who do I need to create an advance directive?

The good news is, for a basic advance directive you don't need a doctor or a lawyer to write one up. This is something you can do on your own. You may just need 1 or 2 people to sign (witness) it. Check with your state on what they require.

Handing out copies

It's good to give copies of your advance directive to more than one person. People who should have a copy include:

- Your healthcare decision-maker
- Your doctor (he or she may even be able to put it in your medical record)
- Your lawyer (if you have one)
- Your family
- You



You can also give copies to anyone else you feel should know. You can even take a copy with you when you travel. That way, if anything should ever happen, someone can let the medical team know you have an advance directive.

Things to Consider

There are a few things to consider when you get ready to fill out an advance directive.

Do I really need one?

Like this stated before, even if you're healthy and independent, no one can predict the future. Hopefully nothing happens, but if it does and you have an advance directive, your loved ones can make the decisions you'd want. If you're older or sick, it's especially important to start thinking about one. If you don't know what you'd want, that's OK. Just start thinking about it, and talking with your family, friends, and doctor. Having the conversation can really help get you thinking and make the process a lot easier.



Organ donation

This is when you agree to let your organs be given to someone who needs them once you're gone (for example, to someone whose kidneys are failing). Sometimes this is part of an advance directive form, sometimes it's not. But if you are interested in donating your organs, make sure your family knows. It can be very surprising for them to find out in the moment, especially if they have different beliefs or if they just never thought about it before.

If you're having a hard time with this decision, a hospital chaplain or social worker or even your state's DMV website can help walk you through any questions or concerns. In many states, you can also sign up to be a donor at the DMV when you get your driver's license renewed, or you can just do it online or with your doctor. But however you do it, be sure to let your family know.

More personal directives

Sometimes you might want other, more personal directives for when you're very sick and near the end. If there's not a place on your state's form, you can write them on a piece of paper and include them with your other advance directives. Things like:

- You'd prefer to die at home
- You want your favorite music played
- You want a member of your religious organization to come visit you when the time comes



Planning for after you're gone

Even though it probably won't be on any advance directive, you can include plans for after you're gone with your personal directives. This might include things like:

- If you want a funeral or memorial service or both
- If you want to be buried or cremated
- Any music or readings you'd like shared at your ceremony
- If there's a certain place you'd like to be put to rest or have your ashes scattered



Keep in mind, while it's great to leave a list of things you'd want for your funeral, it's even more of a gift to help your loved ones through a difficult time when you're around but can't tell them what you'd want. So focus on that and your advance directives first.

Questions to think about

Maybe you're not sure what you'd want with any of the topics mentioned in this summary. Here are some questions that can help get you started thinking:

- **What kind of living situation is (or isn't) acceptable to me?** For example, if I were not able to return to my home, would I still want treatment?
- **Who knows what I want and would be willing to carry out my wishes, even if it was hard for them?** Remember, you're not playing favorites when you choose a healthcare decision-maker.
- **Would I want treatment only if a cure for my illness is possible? Or would I want treatment in any situation?** Don't forget, you're in control of your quality of life.
- **Is there a time when I might accept comfort care (hospice)? If so, when would that time be?**
- **What's more important to me — quality of life or how long I live?** If you're not sure or want more information on disease-centered treatment versus comfort care, you can always ask your doctor for the Emmi program on hospice.

Final thoughts

Remember, choosing to fill out an advance directive is entirely up to you. No one can or should force you to do one. And filling out an advance directive isn't a forever plan. It's a "for now" plan. You can change it whenever you want, or even cancel it completely. It's your call.

Think about whether or not it might be useful to you at some point. Even if you don't think advance directives are for you, talk to your loved ones about your wishes. It's your life. Whatever you decide will be right for you.

Health Information Forms

After you print this summary, you can fill out the following forms. Keep a copy at home and take a copy to your next doctor's appointment.

MY HEALTH INFORMATION

Name: _____

Please fill this out and share it with your doctor.

Date: _____

My Allergies: (for example: penicillin, shellfish, peanuts, latex)

A large rounded rectangular box with a thin grey border, containing 15 horizontal lines for writing. The lines are evenly spaced and extend across most of the width of the box.

MY HEALTH INFORMATION

Name: _____

Please fill this out and share it with your doctor.

Date: _____

Past Surgeries or Procedures:

Have you, or anyone in your family, ever had any kind of bad reaction to anesthesia? Please describe:

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