

The Slightly Sarcastic
but
Honest
Guide to Advance
Healthcare Directives
for
Chronically Ill Young
Adults and Adults-To-Be

by

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Have you already turned 18? If so, welcome. This information is for you. Are you going to turn 18 in the next few years? Welcome, too, you may find this information useful.

So, your social worker or your nurse or your psychologist or some other person has brought you a stack of papers and suggested that you should appoint a Healthcare Agent and fill out a Living Will and your mind screams, “Everyone thinks I’m going to die!!!”

I hate to be the one to explain this fact of life to you, but WE ALL DIE EVENTUALLY!
(That goldfish, you remember the one floating at the top of the tank? It did not

move to a better life in the river via the toilet and the sewer.) Dying is a fact of life about death.

Or maybe, you didn't scream, mentally or out loud, "I'm going to die," because you have always known you will die, perhaps at a young age, and what amazes you is being alive. And since being alive is so awesome and exciting and who knows how long this state of being will last, you are screaming, "Life is too short for paperwork!!!"

You are wrong though, about the Healthcare Agent and the Living Will and your impending death. You, too, are wrong about life being too short for a little paperwork. You are being asked to think about executing an Advance Healthcare Directive

because you are alive, and you have become an adult.

Congratulations on becoming an adult! Not only are you allowed to vote for your government representatives, but you get to make your own healthcare decisions. Filling out an Advanced Healthcare Directive is a moment for you to celebrate. You get to make your wishes known. You get to make decisions that other people must respect.

Depending on your illness, think of all the times adults made decisions for you: big decisions such as which medication or surgeries you should have, little decisions such as what you are allowed to eat or whether you must pee in a cup or from which arm to draw your blood.

While your peers are consuming inordinate quantities of saturated fat, salt, and potassium, and since we are being honest, a few are even imbibing other illegal and/or noxious substances; while they are riding their bikes (maybe even motorbikes) without helmets; foregoing sunscreen; swimming in polluted lakes; you, meanwhile, are perhaps being super-good or maybe you are self-destructing, but either way you probably feel a little annoyed at always being told what you can and cannot do. So, instead of panicking about this document your social worker or whoever is waving in front of your nose, you should be demanding a pen! For once, you get to make decisions about your life!

Adults in the Commonwealth of Pennsylvania have the privilege of making decisions that children are not granted. If you are over 18 or have graduated from high school or are married or are an emancipated minor you may execute an Advance Healthcare Directive.

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Health Care Agents and Representatives § 5452.

Why, you ask, would you want to do this when you aren't going to die in the next 30 seconds?

You want to do this because every adult, healthy or ill, young or old, who wants their healthcare decisions to be followed when

they are unable to communicate should execute this document.

This document gives you the POWER to choose who will speak for you if you cannot communicate and lets you state in advance what treatments or interventions you want or do not want if you are terminally ill.

An Advance Healthcare Directive is a paper and electronic document that usually contains two parts.

Part 1 is the Healthcare Power of Attorney.

In this section you name the person you want to make your medical decisions for

you when you are unable to communicate or express your wishes. If a decision has to be made while you are under anesthetic in surgery, or in a coma, or have a brain injury or impairment, you want to pick who makes the decision, right? This person may decide what medical intervention you receive, what you do not receive, and when to stop a medical intervention.

How do you decide who should be your Healthcare Agent?

You should not pull a name out of a hat. You should not spin in a circle with your eyes closed on a busy street and point and shout “You!”

This is a decision that requires some thought. Thinking might hurt, but it probably will not harm you.

First, there are some people who are not allowed to be your Healthcare Agent.

Your doctors, nurses, medical staff, and anyone who provides your care, or owns a facility that provides you care can NOT be your Healthcare Agent. Since you are ill and probably know more medical people than most this eliminates lots of people you know. But, if your doctor or nurse or provider is related to you by blood (which means your mom, your uncle, a relative) or marriage or adoption then they CAN be your Agent.

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Health Care Agents and Representatives § 5455(a) and § 5455(b).

These are things to think about when choosing an Agent. (Ouch, your poor head –

all this thinking!) You may also be asked to choose an alternate Agent in case your first choice is off spelunking in a cave and cannot be reached.

- Who do you trust?
- Who do you discuss medical decisions with now?
- Who has the guts to stand up to people in positions of power, such as doctors, to make certain your wishes are fulfilled?

Part 2 of the Advance Healthcare Directive contains a Living Will.

The Living Will gives you the opportunity to specify what treatments you want or do not want if you are determined by a doctor to be incapacitated and dying.

How, you wonder, will you know what you want in this future, speculative situation?

- If you wish, you may leave this section blank and allow the person you named in the Healthcare Power of Attorney section to make all the decisions for you.
- You may ask your doctors to tell you more about the treatments listed and make your choices based on their answers.
- If you have already experienced a ventilator or tube feeding or other treatment listed, then you are already the expert.

- You may specify a few of the medical interventions that you want or do not want and leave all the other decisions for your Healthcare Agent to make.
- You may also state that you want a treatment in certain circumstances, but not in other circumstances.

(A word about terminal illness. This is a squishy category. Technically, there are people who may be considered terminally ill for 30 years (an example would be some dialysis patients) and other people who are listed as terminal and then stop being terminal and are still alive. Yet again there are other people, you might be one of them, who truly are terminally ill. Dying is one of the most challenging things most of us will ever do and in the interest of honesty, I must

acknowledge that possibility. Nothing is more annoying than adults who pretend everything is fine and going to be okay when it might not be. BUT, you are alive now, which is why you want to execute an Advance Healthcare Directive.)

How do you execute a legally binding Advance Healthcare Directive?

(Hint: I know you have death on your mind, but executing documents has nothing to do with executing people, I promise!)¹

¹ Execute is a word with many meanings. One such meaning is to put to death. Executing a document means to perform the document in a way that makes it legally binding. Just writing the document is not enough to make it legal. You must perform

After you have completed the written form, you need to sign and date it in front of two witnesses who are age 18 or older. The witnesses cannot be your Healthcare Agent or your healthcare providers. The two witnesses need to sign and date it, too. It is recommended you have it notarized, but that is not required. A notary will need legally valid identification for you and the witnesses. You do not need a lawyer to complete this document.

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Health Care Agents and Representatives § 5452.

or execute the document which in this case means signing and dating it in front of two witnesses 18 or older who also sign and date it and who are not your healthcare providers or Agent.

That is it! You have executed your Advance Healthcare Directive and nobody's dead but the tree it's printed on!

Next!

- Make photocopies of your Advance Healthcare Directive.
- Place the original in a safe place.
- Give copies to your doctors.
- Give a copy to your Healthcare Agent and your alternate Healthcare Agent.
- Make a list of everyone you have given a copy to, so that when you revoke it and make a new Advance Healthcare Directive you can take the revoked² copies back and destroy them.

² Revoke means to take back. If you change your mind about your Advance Healthcare Directive, you can revoke it.

**Are you wondering if your Agent
will speak for you when you are still
able to make decisions and
communicate them?**

No. Your Advance Healthcare Directive only works when you have given a copy to your doctor AND your doctor determines you are not competent.³

³ “Incompetent” is often used interchangeably with the word “incapacitated.” The definition of “Incapacitated person” in **PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Incapacitated Persons - General Provisions § 5501** “means an adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or to meet essential requirements for his physical health and safety.”

On, no! You've executed this document and you've changed your mind and want a different Agent or want to change your choice about tube feeding, what do you do? You revoke it!

You can take it back in two ways. If you are of sound mind, you may revoke your healthcare power of attorney

- by creating a new written Healthcare Power of Attorney in which you state that you revoke the old document.

Note that when the statute says "he" it means she and all genders.

- or by personally informing the attending physician, the healthcare provider, or healthcare Agent that the Healthcare Power of Attorney is revoked.

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Health Care Agents and Representatives §5459(a).

How long does your Healthcare Power of Attorney last?

Unlike milk, your Healthcare Power of Attorney will not go bad, no matter how long it sits around.

A HealthCare Power of Attorney will work until it is revoked either:

- by you, OR
- by the court, OR

- if authorized by the court, the court-appointed guardian-of-the person.

(The second and third might happen, but probably won't so we won't elaborate here.⁴)

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Health Care Agents and Representatives § 5454(d).

When does your Healthcare Agent make decisions for you?

Relax, it will not go into effect because you are taking a nap. Same answer as above.

Two things must occur together.

⁴ A court will sometimes appoint a Guardian of the Person to make healthcare and personal decisions for someone who cannot make decisions, and the court might appoint a Guardian of the Estate to make financial decisions for a person who cannot make those decisions.

1) You gave a copy of the document to the doctor taking care of you; **AND**

2) The doctor taking care of you says that you are incompetent.

(Incompetent is a medical and legal term and is not used the way we do in normal life. When you put dirty dishes in the clean dishwasher and your parent/guardian/stranger inspecting your dishwasher says, “How can you be so incompetent not to notice the dishwasher was clean?” is not the way incompetent is defined here. See definition in footnote 3.)

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Health Care Representatives and Agents §5454(a).

**When do the decisions in your
Living Will get carried out?
Again, totally okay to nap.**

Two events must occur for your living will to be used.

- 1) You gave a copy of the document to the doctor taking care of you; **AND**

- 2) The doctor taking care of you has determined that you are **incompetent and that you have an end-stage medical condition** or are **permanently unconscious**.

(If you are still competent and have an end stage medical condition, your doctors will still discuss with you what you want. They will not read your Living Will and ignore what you say you want.)

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Living Wills § 5443(a).

If you do not create and execute an Advance Healthcare Directive, who makes your health decisions when you are unable to make your own decisions?

Surprise! (Just kidding, this is not a surprise at all.) The Commonwealth of Pennsylvania has a law that will determine who will be your Healthcare Representative if you do not name an Agent.

The state chooses number 1) first and if they are dead or do not exist then the state chooses number 2) on down the list.

List of Pennsylvania's choices:

- 1) Your spouse, unless an action for divorce is pending. Or the adult child who is not the child of the spouse.
- 2) An adult child.
- 3) A parent.
- 4) An adult brother or sister.
- 5) An adult grandchild.
- 6) An adult who has knowledge of the principal's preferences and values, including, but not limited to, religious and moral beliefs, to assess how the principal would make health care decisions. (Long way to say a FRIEND.)

PA Consolidated Statutes Title 20 Decedents, Estates and Fiduciaries: Health Care - Healthcare Agents and Representatives § 5461(d).

About the “everybody thinks I’m going to die” thought Maybe some people think you are going to die, maybe others think you are going to live for decades, most people probably do not know how long you will live or when you might die. But almost all of them are hoping you will be with us for a very long time, as am I!

End



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