

This information could save your life!!!

Medical Durable Power of Attorney VS Living will

My sister and I are not doctors or lawyers and we don't claim to be. Because of our mother, my mother-in-law, my sister's husband/my brother-in-law and this support group, we have been dealing with Parkinson's Disease since 1993. The following is based on fact and our experiences with our own loved ones and the experiences of numerous members of the support group. The advice we are giving here is to help keep a person with Parkinson's from dying prematurely and unnecessarily because of doctor's and the medical profession in general's ignorance of Parkinson's Disease. Unfortunately, the fact is, the majority of doctors know very little about Parkinson's Disease and, as result, a person with Parkinson's life is in jeopardy if that person needs to be hospitalized or sent to an institution like rehab, assisted living or nursing home facilities. For that reason, you need to have all the tools necessary at your disposal to ensure that the Parkinsonian doesn't lose his/her life because of that ignorance.

First and foremost, you need to be armed with a Medical Durable Power of Attorney (MDPOA). You may not have heard of an MDPOA but I know you've heard of a Living Will. They are distinctly different documents and you need to know the difference between them and the pros and cons of both. The MDPOA covers your health care needs all through the rest of your life and can also include your end-of-life directives. The Living Will just covers your end-of-life directives.

Medical Durable Power of Attorney:

1. Document to appoint someone to make your healthcare decisions for you, called your healthcare agent.
2. It's recommended to have backup agent(s) appointed.
3. Effective now or only when you are unable to make your own decisions.
4. Agent has all the powers of medical decision making that you do (see Colorado statute).
5. Agent can get copies of your medical records, consult with doctors and other medical personnel and make all decisions necessary for your care.
6. Agent is to act according to your wishes and values so you need to make sure they know what those are. They should know you very well.
7. No witnesses necessary.

Pros:

1. Someone who knows and cares about you is overseeing and ensuring that the medical care you're receiving is in your best interest rather than in the best interest of a medical facility and/or its staff including doctors.
2. You have someone who will fight to ensure you get the treatment and medication regimen you require to successfully manage your Parkinson's.
3. You can put your end-of-life wishes in the document which would leave the final decision whether to invoke those directives to the agent rather than to doctors (like in the Living Will) who may not understand Parkinson's and, consequently, may have the terminal diagnosis wrong.

Cons:

1. None.

Important Note: A common end-of-life directive is to not be put on a feeding tube. I want to point out that there's a huge difference between an end-of-life feeding tube and a temporary feeding tube needed to get someone back to normal. For Parkinsonians, it is especially critical that you understand the difference. The likelihood of not getting your meds on time in a hospital setting is pretty much assured. If you're in the mid to later stages of Parkinson's and this happens you will likely no longer be able to swallow...not food, water or meds ever again. If this happens, the only way to recover from that is to have a temporary feeding tube inserted to get the meds back into you so you can swallow again. It's a TREATMENT like taking an antibiotic to get over an infection. If you refuse this treatment simply because it's a feeding tube, you will inevitably die. There have been a couple of cases in our support group where the Parkinsonian died because the family refused to allow a feeding tube for treatment because of that patient's end-of-life directives which stated that he didn't want a feeding tube. Because we're talking about Parkinson's Disease which makes the need for this treatment more likely, I suggest that you allow for a temporary feeding tube for treatment in the MDPOA and specify in the end-of-life directives only that you don't want a feeding tube if that is, indeed, the case.

Living Will:

- 1) Document that tells doctors your wishes if you are in a terminal condition and can't make your own decisions.
- 2) 2 witnesses that won't benefit from your death are required.
- 3) Goes into effect 48 hours after 2 doctors certify you are in a terminal condition.
- 4) Doctors must make a good effort to notify the person(s) listed in document that they will be carrying out the directives within 2 days.
- 5) Directives cannot be revoked or altered by anyone unless you indicate in the Living Will that your MDPOA agent can revoke all or part of the directives.

Pros:

- 1) Your end-of-life wishes are documented.

Cons:

- 1) Doctors who likely don't know anything about Parkinson's are making the decision that you are terminal which will automatically put the Living Will into effect thus ending the power of the MDPOA agent if one was appointed by you.
- 2) If your family/caregiver knows that what looks to doctors like you are terminal is actually the result of not getting your Parkinson's medications on time, they will have no power to stop the doctors from carrying out the end-of-life directives.
- 3) Doctors must make a good effort to notify people you've listed but are not required to succeed in reaching those people before carrying out the directives. Even if you had an MDPOA agent and indicated in the Living Will that they can stop the process, if the doctors, for whatever reason, couldn't get in touch with that person, the directives will be carried out regardless.

Recommended website: www.coloroadvancedirectives.com

Reference our website, www.co-parkinson.org, under the 'Resources' tab for the Colorado Statute governing MDPOAs

Our Recommendations:

Unfortunately, the majority of doctors and medical professionals do not understand Parkinson's and the life and death importance of medication management in the mid to later stages of the disease.

The support group has had far too many of our members who were hospitalized for something non-life threatening and ended up dying because of the doctor's ignorance of Parkinson's.

It's for that reason that it's imperative that you have an MDPOA so that you have an advocate who is looking out for your best interest and can and is willing to run interference and fight to get you the proper care that you need. Hospital doctors tend to just concentrate on the reason you are hospitalized and neglect your other conditions. And since most doctors don't know much about Parkinson's they don't realize that if you neglect the Parkinson's they could be causing the death of the patient. Having an MDPOA is the only way to lessen the risk of that happening. You can include your end-of-life directives that you would normally have in a Living Will but without the risk of having no way to reverse an incorrect terminal condition diagnosis. Your agent will have to approve all health decisions before anything is carried out. Personally, I would rather have someone who knows and cares about me making these decisions rather than some random doctor making life and death decisions for me.

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