

Why and how to have end-of-life discussions with your patients:

A guide with a suggested script and some basic questions to use

The medical literature consistently shows that physicians can enhance end-of-life care the most by improving their communication with patients and families.¹ Six aspects of this communication are central in importance:

- Talking with patients and families in an honest and straightforward way
- Being willing to talk about dying
- Giving bad news in a sensitive way
- Listening to patients' and families' experiences and concerns
- Encouraging patients and families to ask questions
- Being sensitive to when patients and families are ready to talk about death

In the last few years, multiple articles²⁻⁷ have documented the following benefits of physicians routinely conducting end-of-life care discussions with patients who have a poor prognosis:

- Better patient quality of life
- Less depression
- Lower costs
- Less aggressive medical care
- Earlier referral to hospice
- Better bereavement adjustment by the family

These studies also show that only about a third of patients with advanced cancer can recall having an end-of-life discussion with their physician. The surprise question, "Would I be surprised if this patient died in the next year?" has been found to identify patients with a poor prognosis who are significantly more likely to die in the next year and who are appropriate candidates for end-of-life discussions and advance care planning.⁸

The following script is offered to West Virginia physicians to assist them in conducting end-of-life care discussions with their patients.

How to discuss advance directives and the Physician Orders for Scope of Treatment (POST) Form with your patients:

A Sample Script for Physicians

Introduction and Asking permission

Speaking to the Patient

You may have heard in the news about good results when doctors talk to their patients about the treatment patients want. One of the areas in which discussions are helpful is end-of-life care. As part of good medical care, I am having this conversation with all of my patients so do not assume that there is something wrong. Would you be willing to talk with me about the types of treatment you would and would not want at the end of life? [If a family member is not present] then ask, "Would you prefer if we spent a few minutes now talking about this topic or would you want to have a family member or close friend be present when we discuss it?"

Discussion about Advance Directives with All Patients

1. To start with, it is helpful for doctors to know who their patients would want to make medical decisions for them if the patients were in an accident or very sick and unable to speak for themselves. The first thing I would like to know is, if you were to become really sick, who you would want to make decisions for you? This should be a person that you trust and that you have talked to about what is important to you in receiving medical treatment. Most patients name a spouse or adult child, but the law in West Virginia allows you to name any family member or a close friend. [wait for the patient's choice of person _____] Does this person know that you have chosen him/her for this role? It is important to ask if he/she is willing to do it. I recommend that you talk to this person to be sure they are willing to make decisions for you and then complete a medical power of attorney, a legal document, to give this person the authority to make decisions for you when you can't make them for yourself. On the medical power of attorney form, you can name a second person to make decisions for you, called a successor representative, if the first person you chose is not available or able to make decisions for you.
2. West Virginia law allows you to combine a living will with a medical power of attorney. The living will only goes into effect when you can no longer make decisions for yourself AND when you are dying from a terminal illness OR when you are permanently unconscious in a vegetative state. If you would not want to be kept alive on machines in either of these conditions, then I recommend that you complete a combined living will and medical power of attorney. There is no charge for these forms. Would you like me to give you a medical power of attorney form or a combined living will/medical power of attorney form?
3. To be legal, the living will and medical power of attorney forms need to be witnessed and notarized. Many businesses have notaries.

[For a patient who is healthy and a reasonable candidate to undergo CPR and mechanical ventilation for an acute illness, then your discussion can stop at this point.]

Discussion about Completion of a Physician Orders for Scope of Treatment (POST) Form

For a patient who has a chronic illness, and especially for patients for whom you would not be surprised if the patient died in the next year, the West Virginia Center for End-of-Life Care recommends that you complete a Physician Orders for Scope of Treatment (POST) form with the patient to ensure that the patient's end-of-life wishes are respected.

4. [Show the patient the POST form and give him/her a POST form leaflet describing the form.]
With this form, I can write medical orders that are respected throughout the healthcare system: in the hospital, in a nursing home, at home, and in ambulances. These are based on your wishes and ensure that you will receive the treatment at the end of life that you want. Because of your _____ (name the patient's chronic progressive medical condition, eg, heart failure or lung disease), I would recommend that we complete a POST form either today or on your next visit. Is this ok?
5. The first section on the POST form is an order with regard to cardiopulmonary resuscitation. Do you know what CPR is? [Explanation of what CPR is: CPR is a medical procedure that combines breathing for the patient, squeezing the heart between the breastbone and the spine to force blood into the circulation, and electrical shocks to the heart given when someone's heart stops beating. CPR is done in an attempt to get the heart started and the person breathing on his own. CPR works best in patients who were previously healthy and whose heart stopped from a drug reaction or choking on food.] State, "CPR is not as successful as most people think." For a patient in your condition, if your heart was to stop and you were to undergo CPR, there is less than a 10% chance that you would survive to leave the hospital. (This is true for patients with severe heart, lung, kidney disease, strokes, and metastatic cancer). I recommend that we do everything we can to help you as long as we can. But if your heart stops I recommend that we keep you comfortable but that we not do CPR. It is very unlikely to help but is likely to harm you by causing broken ribs, brain damage, or injury to your heart and lungs. Does this approach of doing everything that is likely to help but not doing CPR sound okay?
6. The next section on the POST form indicates what level of treatment you would want if you became very sick. There are three options for treatment.

One is called comfort measures. With comfort measures, all the doctors and nurses involved in your care would do everything they could to keep you comfortable wherever you are, whether that is at home or in a nursing home, but they would only send you to the hospital if they couldn't keep you comfortable where you are.

The second option is called additional limited interventions. This would include being sent to the hospital, receiving fluids by vein, having your heart monitored, and receiving medications to correct whatever problem is diagnosed. You would not be sent to the intensive care unit or put on a breathing machine with this option.

A third option is called full treatment. This option includes all medical treatment that could possibly keep you alive. It includes hospitalization with transfer to the intensive care unit if needed and use of a breathing machine. It would include having a tube put in your throat for

you to be connected to the breathing machine and having CPR if your heart stopped. If your blood pressure was failing and you went into shock, it would include medications to squeeze your arteries and treat your shock. It would also include surgery for any problem that would occur.

Which of these options you would want or would you like some time to discuss it with your family at home and discuss it with me again at your next visit?

7. This next section covers whether or not you would want antibiotics if you developed an infection. Most people indicate that they would want antibiotics if it is helpful to improve their comfort. For example if a patient is dying from cancer, she may still want antibiotics to treat a painful bladder infection. Should I mark antibiotics if needed for comfort?
8. This next section covers medical orders with regard to food and fluids given by medical means. It includes fluids by vein and also a feeding tube if you are unable to swallow to eat. For each one you have the choice of receiving intravenous fluid or tube feeding for a long time, receiving it for a limited time such as 30-60 days to see if it is helpful, or not receiving any fluids or food through a tube. If you don't want food and fluids through a tube you will be given food and fluids by mouth as you are able to take them and be allowed to die naturally.
9. I will sign the POST form here and indicate that I had this discussion with you. On the back, I need you to sign the form here. Also there is a space on the back for me to indicate who you would want those treating you to contact if you are unable to make decisions for yourself. Who is that person? What is his/her phone number? Please initial this box so that the person you name can change the decisions we made as your condition changes and even complete a new POST form if appropriate. Please sign the form in the space for patient's signature.
10. I will give the completed POST form to you. I suggest that you keep it on your refrigerator with a magnet so that in case of an emergency it could be easily found. Also, West Virginia is developing an electronic registry to ensure that your wishes for treatment are known to the doctor treating you. Your POST form and advance directives can be entered in this registry so that doctors treating you wherever you are in the state could go on the Internet and read them. The doctor would need to have a password and your wishes would be kept confidential. Yet, it would be very helpful for them if you got sick, needed to be transported to an emergency department, and you could not make decisions for yourself. The POST form has a box here that you can initial to indicate that it is alright for me to fax a copy of this form to the registry. I recommend that we do this. OK? I will fax a copy to the registry and then give the POST form back to you?

Thank you for having this discussion with me today. Now I know the types of treatment that you do and don't want, and I will be able to respect your wishes if you become too sick to tell me what you want at the time. Also, it will make it much easier for your family because any medical decisions that will be need to be made for you can be made based on what you have said you would want. Your family won't have to guess what you would want in a future

situation. If you change your mind about anything you have told me today, please let me know. We can complete a new form for you.

Basic Questions for End-of-Life Discussions⁹

1. What is most important to you as you think about the end of life?
2. Where would you like to be during your final days?
3. Who would you want to care for you?
4. What types of treatment would you want or not want?
5. Who do you want to make decisions for you if you are unable to speak for yourself?
6. Would there be anything left unsaid if you were to die suddenly?

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