

## Doctors' Page

The following provides guidance on how to conduct advance care planning discussions with patients and their health care proxy / family using the Medical Directive.

### **Step 1: Start patient-proxy-family, home-based advance care planning discussions**

A member of your health care team – a nurse or social worker, for instance – can do this step for you.

It is best to start advance care planning as part of a routine visit. If your patient has had a recent diagnosis or decline in health you may feel it is necessary to start the process right away. If there is time, consider first allowing the patient to adjust to the new health status.

Explain to the patient that advance care planning is a prudent, routine part of care for everyone. Sample language from a clinician follows:

*“I like to bring up advance care planning with all my patients, especially while they are in stable health. It is part of knowing your health care preferences. There is no other bad news or anything prompting me to raise this; like insurance and estate planning, it is simply a prudent thing to do. I have done it myself and I am in good health.”*

Show the patient the Medical Directive worksheet and explain how it will be used in something like the following language:

*“This is a worksheet that shows some hypothetical situations that can take away a person’s ability to make their own decisions. You can have these copies [or direct him/her to [www.medicaldirective.org](http://www.medicaldirective.org) ] to work through with a pencil and eraser.*

*It is best to do it with whomever among your family and friends who would be likely to be caring for you if you were to be that sick. That should include your health care proxy. If you don’t have one, think about whom to ask and include that person in the discussion.*

*The idea is to go through the scenarios and then think: what would I want if I were to be like that. Then you select among possible goals for care. If you want to go further and select treatment options, you can do that to.*

*We [you and the doctor] will go through it at your next visit, so bring it with you.*

### **Step 2: Find the patient’s threshold**

This step should be done by a nurse or doctor.

The aim of this step is to go through the patient's penciled-in preferences and what their threshold is for shifting from wanting care with curative to care with palliative intent.

**a. Goals of care threshold:**

The Medical Directive has scenarios that are arranged as much as possible by prognosis and disability. In each scenario the patient will have selected among the options for goals of care.

Research shows that goals of care predict specific treatment choices, so this is the first thing to know about a person's preferences for care.

To find the patient's threshold for goals of care, look to see where he/she shifts from wanting curative intervention to comfort-oriented care. Point that out to the patient to see if it feels right to him/her. If it does, that gives validation for his/her preference.

Some patients, especially the chronically and seriously ill elderly, may want palliative care in all scenarios. That means they have already crossed their threshold. Others may have no threshold for palliative care. That means they are not ready to reconcile to the possibility of death under any circumstances. However, the great majority of patients have a threshold in the range of scenarios in the Medical Directive.

**b. Intervention threshold:**

Each scenario in the Medical Directive has, in addition to goals of care options, potential life-sustaining intervention options. These interventions are listed in approximate order of burdensomeness. Note that pain treatment is about comfort so ignore responses to that option for this exercise.

Look at the pattern of selections to see at where he/she shifts from wanting to not wanting the intervention. The scenarios that are at the patient's threshold for goals of care may be most revealing.

These two thresholds, like the latitude and longitude in the coordinates of a global position, describe most important features of a person's disposition. Tell the patient to be sure his/her proxy and other relevant people know his/her threshold.
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**c. Values:**

In addition to a person's thresholds, he or she may have personal experience or values that make for an exception to the general pattern. For instance, a person may feel strongly about living with dementia, or about use of artificial nutrition. Preferences that follow these beliefs can also be noted and pointed out to the patient for affirmation. Such validated wishes should also be made known to the proxy and relevant others.

**d. Errors**

Occasionally, a person pencils in a preference that makes no medical sense. If you find one, ask what the patient had in mind and help translate that into a medical decision that fits.

**Sample threshold:**

The below is a sample of one person's preferences and revealed thresholds.

<http://medicaldirective.org/DoctorPageFrontpagesInsert.pdf>

This patient's threshold for switching from wanting curative-intent treatment to wanting palliative care lies at the transition to Scenario F. In this situation she has gone from wanting palliative care and no life-sustaining intervention to wanting treatment with curative intent, including life-sustaining treatment.

It is reasonable to infer that if scenarios and treatments come up that are not specifically listed in this worksheet, if seem to fall to one side or the other of the patient's threshold, the doctor and proxy can be guided by that to intervene accordingly with curative or palliative intent.

**Step 3: Documentation**

Check that you, the doctor, are comfortable that you could honor the patient's preferences, and that their proxy is also. If not, revisit the decisions and who is in the role of doctor or proxy until all are comfortable. Then, if the patient is also settled with his or her own choices, you may offer to ink-in the worksheet and make it part of the medical record. If your medical record uses different systems for advance care planning, use an open text area to document

1. the personal threshold;
2. the scenario based goals; and
3. the treatment choices that the patient has expressed.

**Note:**

- Find your own threshold. This will help you to understand what your patients and their proxy / family are doing as they do their advance care planning. For a web video editorial introducing with a demonstration how this happens, go to: [link will be available shortly]
- Some patients may not have a clear threshold. Some may need time to clarify their thinking.
- Patients may change their preferences over time or based on experience. Check with your patient periodically and help them to make any necessary updates in their medical record and documents.
- In all cases, use the patient's expressions as a guide to real time decision-making and work with the proxy, family and team to make optimal, hopefully consensual, decisions.