Deciding Tomorrow... TODAY.
Provider’s Guide
No one should end the journey of life alone, afraid or in pain. Deciding Tomorrow... Today is a program and toolkit developed by Nathan Adelson Hospice. The purpose is to help facilitate the communication of end-of-life values and priorities between individuals, family members, friends, faith leaders, other important people and physicians.
Deciding Tomorrow... Today Provider’s Guide includes:

1. Why should providers care if their patients have an advanced directive?
2. How can we help our patients achieve their goals?
3. Initiating the discussion
4. Clarifying prognosis
5. Identifying end-of-life goals
6. Developing a treatment plan
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8. Physician Order for Life Sustaining Treatment (POLST)
Ruth was a Jewish woman in her late 70s with end-stage Chronic Obstructive Pulmonary Disease (COPD) who was rushed to the hospital because she couldn’t catch her breath. At the hospital she told a nurse that she did not want artificial feeding or to be resuscitated if something were to happen to her. However, she did not want to sign a Do Not Resuscitate (DNR) order because she said it was against her religion. Her condition declined and she was intubated and cared for in the Intensive Care Unit. Her closest family members were two sisters who lived out of town but arrived a few days after she had been in the hospital. One sister was the Durable Power of Attorney (DPOA) for Health Care, but did not know her sister’s wishes regarding treatment.

As a part of the Palliative Care Team, I met with Ruth’s two sisters about her prognosis. I explained the option of extubation and hospice care. Although there was a possibility that Ruth would breathe on her own after she was extubated, it would not make sense to also remove the endotracheal tube. If her sisters wanted her re-intubated and, if she had additional difficulty breathing once she was extubated, she would likely need a Tracheostomy and Percutaneous Endoscopic Gastrostomy (PEG) and tube.

Ruth’s other (non-DPOA) sister immediately said, “There is no way my sister would want to be extubated and I will not agree to hospice.” Since Ruth was conscious, we were able to explain the options to her. She was able to nod “yes” to removing the tube and “no” to re-intubating if she could not breathe, even though she may die.

The team left the room and Ruth’s other sister stayed behind. After awhile, the sister came out of Ruth’s room and said that Ruth’s sister did not want the tube removed. I asked Ruth’s other sister (with DPOA) to make the decision. She was torn and overwhelmed and could not make the decision. To further complicate matters, the sisters were not in agreement about what to do. Several days passed and Ruth’s sister with the DPOA could still not make the decision to extubate. I met with her again and explained what was happening to Ruth’s organs. Her sister, full of uncertainty and guilt, and in discord with Ruth’s other sister, decided to have Ruth extubated. The other sister vowed to never speak to her again.

As a hospice and palliative medicine physician, I live this story every day with different patients and different families. So much of the pain, suffering and family discord can be prevented if physicians had a conversation about advance care planning with their patients much earlier.

Why I care if my patient has an advance directive...

Warren Wheeler, MD
Nathan Adelson Hospice
If patients planned better, they could possibly live longer, be more comfortable in their home, and experience a more dignified death, surrounded by family and friends. When advance directives are in place, overall spending is lower and there is less likelihood of a patient dying in a hospital.

Why should providers care whether patients have an advance directive?

On the other hand, if a terminally ill patient who does not have an advance directive is hospitalized and stops breathing, they are intubated and placed on a ventilator that pushes air into their lungs to keep them artificially alive. If they stop eating, a percutaneous endoscopic gastrostomy (PEG) is inserted in order to infuse liquid nutrition, which can cause edema and pulmonary congestion. If the patient’s heart stops, cardiopulmonary resuscitation (CPR) is conducted, which, in a frail patient, may result in broken ribs, a punctured lung and brain damage. Death is prevented and life is extended, but the patient is still terminally ill. The patient will most likely die in a hospital, surrounded by doctors and nurses while the family is in another room, nervous and scared.
One concern many medical providers have is that providing true prognostic information will take away a patient’s hope. The idea, however, that receiving unfavorable news about prognosis will cause harm is unsubstantiated.\(^1\)\(^,\)\(^2\) In fact, in one study of children with life-threatening illnesses, knowing the complete prognosis increased parental hope.\(^3\)

Discussing the topic of end-of-life may be the hardest part of a provider’s job. When providers are uncomfortable delivering bad news, they may avoid the discussion or relay unrealistic optimism.\(^4\) This can leave the patient confused and feeling betrayed when they eventually learn the truth. One way to help ease the discomfort and increase confidence in delivering bad news is to have a plan and strategy for determining the patient’s values, wishes and distress level when they receive the information. A discussion with the patient about disclosing bad news will help the providers gather information about the patient’s readiness to receive it. The information should correlate to the patient’s wishes and be delivered with compassion.

“How is a theological virtue, but has nothing to do with the statistical probability of a positive clinical outcome for someone who is terminally ill.”

Warren Wheeler, MD, Nathan Adelson Hospice

How can we help our patients achieve their goals?

We ask our patients to complete an advance directive. We ask them how they want to live at the end of their life. Research shows that patients want their doctors to speak with them regarding advance care directives and they want to have this talk early. We have the tough conversations about CPR, artificial feeding and comfort care. Discussions with patients who are dying and their families address a wide range of concerns including: fears about dying, understanding prognosis, achieving important end-of-life goals and attending to physical needs. Good communication can facilitate the development of a comprehensive treatment plan that is medically sound and in accordance with the patient’s wishes and values.
Guide to Talking about End-of-life Care

Step 1: Initiating discussion

Establish a supportive relationship with patient and family.

“I know this is a very difficult time for you and your family. You have never been this sick before and I know that it must be frightening to you. I want you to know that as bad as it is, we will deal with it together.”

Appoint a surrogate decision maker.

“You will go through a lot of hard treatment and have good days and bad days. If you can’t make decisions for yourself, whom should I turn to?”

“Who should make these decisions for you if you can’t speak for yourself?”

Elicit general thoughts about end-of-life preferences.
Go beyond stock phrases with probing questions.

“What represents a good quality of life?”

“What concerns you most about death or dying?”

“How do you wish to live the remainder of your life?”

“Some people want everything possible done to delay death. Others don’t want dying to be prolonged. Where do you draw the line?”

“You said that you don’t want to suffer—please define what suffering means to you.”

“You’ve indicated that you don’t want to be a burden to your family—please define what being a burden means to you.”

“You’ve indicated that you don’t want to be kept alive as a ‘vegetable’—please define what that means to you?”

Step 2: Clarifying prognosis

Be direct, yet caring.

“I want to be certain that I have clearly explained your medical situation. What is your understanding about what is ahead for you?”

Be truthful, but sustain spirit.

“While I can’t cure you, there are still many things I can do for you. I want you to be able to speak openly with me, so I can best help you. No matter what happens, I can be here for you—you are not alone.”

Use simple everyday language.

“This cancer is getting the better of you. The treatments that have helped you in the past are no longer working. I understand your desire to feel better and to be better—but, unfortunately, it is not realistic.”

Step 3: Identifying end-of-life goals

Facilitate open discussion about desired medical care and remaining life goals.

“We have talked about your illness and poor prognosis. You have told me about how you want to spend your final time. I also need to know your thoughts about using cardiopulmonary resuscitation (CPR).”

“As your doctor, I want to ensure we are focused on doing things that might help you and bring you comfort. What things are most important to you? How do you wish to spend your remaining time?”

“With some patients we use cardiopulmonary resuscitation. This means that if your heart stops beating, we would try to use electric shock and chest compressions to get your heart beating again. If you stopped breathing, we would attempt to assist your breathing with a tube in your airway. On television, these treatments appear to work, but in real life, they are rarely successful.”

Recognize that as death nears, most patients share similar goals: maximizing time with family and friends, avoiding hospitalization and unnecessary procedures, maintaining functionality and minimizing pain.

“From what you’ve told me, here’s the plan I suggest. Please let me know if I am correctly representing your views.”

“Given that being at home and spending time with your grandchildren are most important, that is what we will focus on. I can arrange to have nurses see you at home as needed. Let’s ensure we design your medical care so that you can accomplish what you want with your remaining time.”
Step 4: Developing a Treatment Plan

Provide guidance to understanding medical options.
Make recommendations regarding appropriate treatment.

Clarify resuscitation orders

“You previously told me that when your time comes, we will let nature take its course. I will make sure you are comfortable. We will not plan to use cardiopulmonary resuscitation, breathing machines or an intensive care unit. Am I correctly stating your preferences?”

Initiate timely palliative care, when appropriate.

Possible Counter Responses

“I am feeling fine, so we don’t need to talk about this now. We can wait and handle things as they come up.”

“We’d both like to think that you will always be healthy and able to make decisions for yourself, but things can change suddenly. You could have an accident or develop a serious condition and not be able to speak for yourself. So, making your wishes known now will help everyone care for you the way you want.”

“This is too hard (or morbid or depressing) to talk about.”

“While it can be hard to talk about, it’s very important for your family. When left to guess your wishes, family and friends often feel anxious about making the right decision. They may disagree and not know what to do.”

What the Evidence Shows

• Patients want to discuss end-of-life issues with their doctor.  

• Patients do not have anxiety or distress as a result of hearing the truth about their illness.  

• Patients with metastatic non-small-cell lung cancer who had early palliative care and less aggressive care lived nearly three months longer than patients receiving standard care.  

• Advance care planning reduces stress, anxiety and depression in surviving relatives.

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Physician Order for Life Sustaining Treatment (POLST)

Another important aspect of advance care planning is legal considerations. Nevada state law requires an attending physician to complete a form that summarizes the wishes of an individual regarding life-sustaining treatment with any patient who has a life expectancy of less than five years. This is more than an advance directive; it provides specific instructions for someone who is terminally ill. The Physician Orders for Life-Sustaining Treatment (POLST) form is available at www.nevadapolst.org.

A POLST form differs from a DNR order in one important way: A POLST form also includes directions about life-sustaining measures in addition to CPR, such as intubation, antibiotic use and feeding tubes. It may also indicate whether a person has chosen to donate their organs after death. The POLST form helps medical providers understand the person's wishes at a glance, but it is NOT a substitute for a properly prepared advance directive and Durable Power of Attorney (DPOD) for Health Care. A physician cannot be disciplined or face legal action if:

• Treatment is withheld in compliance with the POLST form and the medical orders reflected on it;  
• The provider is unaware of the existence of a POLST; or, 
• The patient, their agent, parent or legal guardian overrides it (any of these may override a POLST form)

No single conversation can cover all of the decisions families may face, but discussions can provide a shared understanding of what matters most to our patients.

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“85% of Americans want to die at home - yet 50% die in a hospital.”

For more information, go to www.decidingtomorrowtoday.com