

Palliative Care and Shared Decision Making

Palliative care can help to relieve discomfort and stress for people with serious illnesses. It can be given along with treatments that try to cure the illness.

Shared decision making is a conversation with your doctor about treatment choices. Usually, treatment decisions are made when your doctor recommends a treatment and tells you about the possible pros and cons. But there's often more than one way to treat an illness. In shared decision making, you and your doctor discuss various treatment options. A decision aid can show you the pros and cons of those different treatments, as well as their possible results.

Taking part in shared decision making can help you to make important palliative care decisions. It can bring to light the personal goals and values of you or your loved one. In addition to personal goals and values, the cost of treatment can be an important part of making choices about palliative care.

FAIR Health has created three decision aids for shared decision making during palliative care. The decision aids are free and include cost-of-care information. They can be used by patients or their families to help make choices about staying on:

- Kidney dialysis for kidney failure;
- A feeding tube and other feeding options for nutritional assistance; or
- Mechanical ventilation.

You can [access the decision aids here](#).

If you or a loved one has a serious illness, palliative care can help relieve discomfort and stress. Shared decision making is a conversation with your doctor about your treatment choices.

What Is Palliative Care?

Palliative care is medical care that tries to relieve discomfort and stress for people with serious illnesses. It focuses on improving quality of life for patients and their families. Palliative care doesn't try to cure the illness. Instead, it aims at relieving symptoms of the illness, like nausea, fatigue or having trouble sleeping. You can get palliative care at any stage of the illness, starting when it's first diagnosed. People who are getting palliative care can still get treatment that may cure the illness.

A palliative care team includes doctors, nurses and other specialists in this type of care. The team doesn't replace your regular doctors. Instead, they work with them to provide you with extra support. Palliative care can be given for serious illnesses, including kidney disease, heart disease, lung disease, cancer and others.

What Is Shared Decision Making?

Treatment decisions usually get made in this way: Your doctor recommends a treatment and tells you about the possible pros and cons. If you agree to the treatment, you sign an “informed consent” document.

Often, though, there’s more than one way to treat a serious illness, and there isn’t one “right” choice. This is when shared decision making can be helpful. Shared decision making is a way of looking at your treatment options and discussing them with your doctor. Decision aids can be useful when having this conversation with your doctor. Decision aids show you different treatment choices, their pros and cons and the possible results of those choices.

Shared Decision Making and Palliative Care

Palliative care can be given for serious illnesses like end-stage kidney disease (ESKD) or advanced cancer. In cases like these, shared decision making can provide a way for a patient, or a patient’s family, to think about what kind of care would best fit the patient’s needs and goals. For instance, someone with ESKD could use a decision aid to help him or her choose between remaining on kidney dialysis or stopping it.

Decisions about palliative care for serious illness are extremely personal, and there are no right or wrong choices. For example, one person may wish to be relieved of the discomfort of dialysis. That person may decide to go off of dialysis and let nature take its course. Another person may have the goal of seeing an important event take place—for instance, the birth of a grandchild. For that person, seeing the grandchild born is far more important than any discomfort he or she may have from dialysis.

Taking part in shared decision making can help make the goals and values of you or your loved one clear to you. Then it may be easier to make important decisions.

FAIR Health Decision Aids for Palliative Care

In addition to personal goals and values, the cost of treatment can be an important part of making choices about palliative care. Until now, decision aids haven’t included treatment cost information. FAIR Health, with funding from The New York Community Trust, has created three decision aids for palliative care shared decision making. We’ll be introducing more decision aids in the future. We created the aids with Dr. Glyn Elwyn of the Dartmouth Institute, a recognized expert in shared decision making.

These palliative care decision aids can be used by patients or their families to help make choices about staying on:

- Kidney dialysis (for patients in kidney failure);
- A feeding tube and other feeding options for nutritional assistance; or
- Mechanical ventilation.

The aids include information about different treatment options, and their possible results, in these situations. They also include information about the costs of those treatments. The decision aids are free and are available on this website. You can [access the decision aids here](#).

They're for your use, to help with discussions with your doctor. The aids may help you make the best possible decision for you or your loved one.

Reach Out for Help

Care decisions, especially care decisions for serious illness, can be very difficult to make. You may find it helpful to speak to a religious advisor, a professional in psychology (such as a social worker) or someone else whose guidance you value.

Resources

If you or your loved one is living with a serious illness, getpalliativecare.org can help you find [out](#) more about palliative care, decide if it's right for you, find a doctor and connect with other patients and families.

Another site, PalliativeDoctors.org, will help you learn more about doctors who specialize in palliative medicine. You can also find out about getting started with palliative care, read patient stories and see information about hospice care.

Your Action Plan: Make Decisions about Palliative Care

- If you think you'd like palliative care, talk to your doctor. Usually, you need a referral from your doctor for palliative care services.
- If you're not clear on anything about your illness, or about what's likely to happen with the illness in the future, ask your doctor to explain.
- Ask your doctor to go over any treatments for the illness that you may have in the future. Let your doctor know if there are any treatments you would or would not like to have.
- Talk to your doctor about your goals. For instance, if your goal is to see your child graduate from school, let your doctor know that.
- Let your doctor know if you have any personal, cultural, religious or spiritual beliefs that could have an effect on your care decisions.
- Give your doctor a copy of your living will or health care proxy, if you have one.