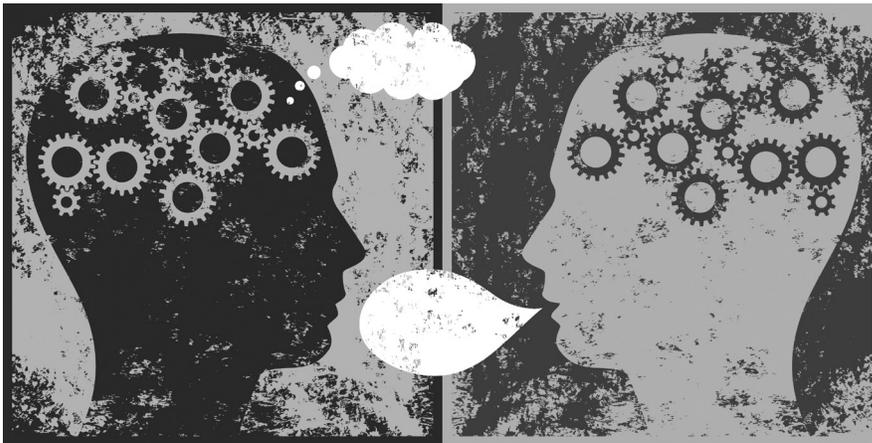


Talk About It!

A Practical Guide to Help
Communicate Your Health-Care
Wishes to Others



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Introduction

WELCOME! The purpose of this toolkit is to improve understanding of your wishes and values. What type of care would you want in an emergency or if you were facing a medical crisis? If you couldn't speak for yourself would someone else know your wishes and make the right decisions for you?

It is important to talk with someone close — a family member or good friend — about what is important to you so that in an emergency situation decisions about your care would be based on your wishes.

In hospitals around the country there are many struggles with care choices during medical crises. Both families and the health-care team wonder if they are doing the right thing — doing what the person would want.

The struggles occur because we all avoid talking about these subjects. It can be emotional and overwhelming to discuss choices about medical care.

What is known is that when people have talked about their wishes in clear ways with their decision makers, both they and their families feel better. If faced with a medical crisis, the decision maker has less anxiety because he or she understands what the person would want.

What is this toolkit about?

This packet is about values and talking with your decision makers about what is most important to you. This packet is divided into four parts.

The four sections are:

- CPR (cardiopulmonary resuscitation)
- Mechanical ventilation (breathing machines)
- Dialysis (kidney machines)
- Artificial feeding and fluids

These four topics are what we call the major life-supportive treatments. People don't always know how they feel about these things and oftentimes they need more information.

In each section you will find a description of a treatment and then some examples of when that treatment might be offered. At the end of each section there are questions and talking points for you to think about. Please look at each of these treatments and talk about them with your family and the person you have chosen to be your decision maker.

The more you talk about them the more people close to you will understand your point of view about these topics.

Hopefully, your decision maker will never have to use this information, but in any case he or she will be ready and will know your thoughts and feelings about each treatment.

Advance directives

Advance directives are legal documents, and there are two different types. One is called a *durable power of attorney for health care*, which names the person you choose to make health-care decisions for you if you are unable. The other form, called a *living will*, describes your wishes about medical care at the end of life.

Advance directives are important and useful documents, but they often still leave the decision maker trying to understand the person's wishes. It is very important to talk to your decision maker about your wishes, even if you fill out advance directives. If your wishes change over time, advance directives can be changed, too.

Advance directives are not part of this packet (toolkit). However, they can be prepared along with this packet, as the packet is focused on the conversation and shared understanding that should go along with these legal papers.

How to begin

It is important to talk about your wishes with your decision maker(s) at a time when this discussion is the only thing going on.

- Turn off the TV
- Avoid interruptions
- Find a comfortable place to talk

Remember, this toolkit is in parts so everything doesn't have to be done at once.

You might find that others do not want to do this activity with you. They may say things like, "Oh, you are healthy, so why should we talk about this now?" or "This is depressing — I don't want to do this." You need to be ready for this type of reaction and you might want to say, "I know I'm healthy right now but I would feel much better if we could talk about this while I am healthy." Or, "It is very important to me that we talk about this. Can you please do this for me?"

Conversations about these topics are not just a one-time thing. Your wishes can change over time.

What is important is to begin these talks. Once you have begun, talking about these topics in the future will be much easier and you can build on each discussion.



CPR (Cardiopulmonary Resuscitation)

CPR is something that can be tried when someone has stopped breathing and/or when their heart has stopped beating. CPR involves repeated pushing on the chest to try to pump the blood through the body. Also during CPR, air is pushed in and out of the lungs. This is done by either another person taking his or her mouth, covering yours, and blowing air into your lungs mouth to mouth or, if one is available, through a mask. In a hospital or if the medics are doing CPR, a tube will be put into your throat and into your windpipe (trachea). Air will be pushed into your lungs through this tube.

Also during CPR, medics or hospital staff may use electric shocks and/or medications to try to restart the heart.

Does CPR work?

Now that you know what CPR is, it is important to know what the chances are that it will work. CPR works about 4 percent to 20 percent of the time.¹

Unlike what you might see on TV, CPR does not work much of the time. There are several things that make the chances of success less likely. If a person has heart or lung problems or other health problems, the chances that CPR will work are less. If a person has stopped breathing and/or his or her heart has stopped and help does not come quickly, the chances that CPR will work are less.

When the heart stops beating the person has died. CPR is tried to see if the heart and lungs (breathing) can be restarted. If a person has gone several minutes without enough oxygen getting to the brain, even if CPR works to restart the heart and the lungs, there can be problems with permanent brain damage because of the lack of oxygen.

You have a choice about whether to have CPR. Since the chance of success with CPR really can depend upon your health, CPR is an important thing to talk about with your doctor. You need to decide what is best for you.

CPR in the hospital

In a hospital, all people get CPR unless the doctor writes an order in the chart that says, “No CPR.”

In Washington state there is a form called *POLST (Physician Orders For Life Sustaining Treatment)*. This form covers many treatments that are talked about in this toolkit. It also has a part about CPR. If you want to let people know about your wishes for CPR, then that part can be filled out. You would get a POLST form from your doctor. You sign the form and when the doctor signs the form it becomes a doctor’s order.

Once a POLST form is completed, you keep it. The doctor also gets a copy. If you ever need to go into a hospital, you can bring the form and have a copy made for your chart.

CPR outside the hospital

In your house or in the community, if an ambulance is called, the medics will do CPR. When they are called to a house they will look to see if the person who is ill has a POLST form. They only look in two places. They look on the refrigerator and they look on the back of the bedroom door. If you have a POLST form and you do not want CPR, you should put a copy of the POLST form in one of these places.

Examples

Some people have very definite feelings about CPR, while for others their choice about CPR may change as their health changes. Here are a few examples to think about — these examples may help you talk with your decision makers.

Example 1

You are in good health and one day you have a heart attack. Your heart stops beating. *Would you want someone to start CPR and call 9-1-1?*

Example 2

Your health is poor. You are unable to walk around one block. It seems like you are always seeing your doctor because of your poor health. You have something called congestive heart failure, which means that your heart isn't working very well and this causes your lungs to fill up with fluid. You are always short of breath and tired all the time. You are alert and able to enjoy time with your family and friends, but your physical activity is very limited.

One day you have a heart attack and your heart stops beating. *Would you want someone to start CPR and call 9-1-1?*

Example 3

You have cancer and your doctor has told you that you have about six months to live. You are dealing with pain all the time and need to take pain medicine to try to get some relief. You are able to get around some, but the pain sometimes stops you from doing too much. Though you are able to visit with your family and friends, you get tired easily.

One day you have a heart attack and your heart stops beating. *Would you want CPR started and 9-1-1 called?*

Example 4

You have dementia and though you are not in any physical pain, you do not know who your family or friends are when they come to visit you. You require someone to take care of you 24 hours a day.

One day you have a heart attack and your heart stops beating. *Would you want CPR started and 9-1-1 called?*

Talk about it

Did your wishes about CPR change because of any of these examples?

Is there anything else you need to know in order to make up your mind?

When looking at these examples, would it have made a difference if you had pain?

When looking at these examples, would it have made a difference if you couldn't recognize family and friends?

What types of things are important to you around quality of life (thinking clearly, comfort, physical abilities)?

Notes

Mechanical Ventilator/ Respirator (Breathing Machine)

Mechanical Ventilator/Respirator (Breathing Machine)

THERE ARE MACHINES that are used to artificially breathe for a person who cannot breathe on his or her own. Air is pushed into the lungs. This machine is connected to a tube that has been placed through the person's nose or mouth and into the windpipe (trachea). The machine is programmed to push a specific amount of air into the person's lungs, and do it several times a minute.

Some people who are paralyzed are unable to breathe on their own. They can live for years being connected to portable breathing machines.

During surgery, while the patient is asleep (unconscious) from the anesthesia medicine, the patient is connected to a breathing machine. When the anesthesia medicine is stopped and the person begins to wake up, the breathing tube and machine are removed because the person can now breathe without help.

When we talk about being connected to "machines," being connected to a breathing machine is often the image we think about.

In situations where a person has had an emergency or a significant illness, he or she can be placed on a breathing machine as part of CPR (cardio-pulmonary resuscitation). Sometimes this will mean that the person is connected to this machine for days, weeks and even months.

If a person is on this machine for weeks, the doctors will need to cut a hole in his or her neck and into the windpipe (trachea) and connect the tube straight from here instead of through the mouth or the nose. They need to do this to prevent scarring of the upper airway and throat.

If the person is not getting better from the illness or is not going to get better, the health-care team may approach the person's decision maker to talk about removing the breathing machine.

Sometimes the breathing machine is the only thing that is keeping the person alive. These machines are considered "artificial life support" because the person cannot breathe on his or her own.

Examples

Example 1

You have had a severe allergic reaction to a medicine and have had trouble breathing. With emergency medicine, this problem can be fixed within days or hours. You may need to be on a breathing machine until the swelling in your throat and lungs is better. *Would you want the breathing machine?*

Example 2

You have had pneumonia that has gotten worse and worse, and you are really struggling to breathe. The doctors have you in the hospital and are giving you medicine for the pneumonia, but you are not getting better very quickly. You are having trouble getting enough air and your oxygen levels are low. The breathing machine is something that the doctors would consider to give you more time to get better with the medicines. *Would you want the breathing machine?*

Example 3

It is now three weeks later and you are still not better with your pneumonia. You are on the breathing machine and they need to cut the hole in your airway (trachea). The doctors are not sure you are going to get better with this pneumonia. *Would you want to continue with the breathing machine?*

Example 4

You have been found after having a heart attack and are not responding. You have no heartbeat and are not breathing. CPR is done and the medics are able to get a heartbeat. They put the airway tube in as part of the CPR and take you to the hospital. You are now in intensive care and you are connected to a breathing machine. After a few days of tests, the doctors know that you did not get any oxygen to your brain for many minutes during the heart attack. You have damage to your brain from that lack of oxygen. You are not waking up and they do not think you are going to wake up. They are able to keep you alive with the breathing machine and other life support. *Would you want the breathing machine continued?*

Mechanical Ventilator/Respirator (Breathing Machine)

If so, how long would you want the doctors to keep you on the machine?

Would you want to stay on the machine and live in a facility that provides care for people who do not wake up but need the breathing machine to live?

Talk about it

What made a difference to you about accepting the machine or not accepting the machine?

Does your chance of recovery or getting better make a difference?

Would it be OK to be kept alive on a machine like this? Would you need to be awake for this to be OK or is it OK to not be alert (unresponsive or in a coma) but needing the machine to survive?

Notes

Artificial Nutrition

WHEN A PERSON can no longer eat food or drink liquid, the idea of artificial feeding or artificial nutrition may be discussed.

There are many reasons that people might not be able to eat. Perhaps they have had a stroke and have physically lost their ability to safely swallow. Perhaps they have stopped eating because of a disease that is worsening, or because of a general decline that can come with advanced age. Maybe they are in a coma or unconscious and are not waking up to eat.

What is artificial nutrition?

Artificial feeding/nutrition can be given in several ways. There can be a tube placed through the nose and into the stomach — this is called an NG tube or a nasogastric tube. This tube can be put in by a nurse or a doctor and doesn't need surgery.

Another option is a tube that is put directly through the skin and into a person's stomach. This is called a PEG tube or gastric tube. Depending on the situation, this procedure is done in either the person's room or in an operating room.

Another tube that is placed in surgery is called a J tube or jejunostomy tube. This tube is put directly into the bowel just below the stomach.

All of these tubes are used to put nutritional liquids directly into the digestive system. This is how artificial nutrition works. The person would have the tube connected to a pump that can deliver formula, water and medicine. If a pump isn't used, then a caregiver can pour or push the fluids into the tube.

If the gut (digestive system) doesn't work, artificial nutrition can also be given in a special intravenous (IV) fluid called TPN (total parenteral nutrition). To be getting TPN, a person needs to have a large IV line called a central line that would be surgically placed into a large vein close to the heart. TPN is given with an IV pump and usually is connected eight to 12 hours a day.

Does artificial nutrition work?

Artificial nutrition, in most situations, will help to support life. For example, in a person who has had a stroke it will not reverse the effects of the stroke, but it will provide nutrition to sustain life. In the stroke example, artificial nutrition might be temporary and only used until the person can regain his or her ability to swallow. If the person never regains the ability to swallow, then it would be permanent.

There are many situations where people who were permanently unconscious were given artificial nutrition. Because of these artificial feedings they lived for years in the same condition.

Sometimes artificial nutrition is not helpful. If a person has dementia or Alzheimer's disease, starting artificial nutrition has not been shown to keep the person alive any longer.²

In other situations, such as a spinal injury with paralysis, the artificial feedings may be very helpful in maintaining the person's nutritional state. Nutrition helps to prevent infections and maintain life so that the individual can get treatment for his or her injury.

Examples

Example 1

You have had a stroke. The effects of the stroke are that you have weakness on your left side. You can talk but your speech is slurred. You are alert and fully aware of your surroundings. You also choke when you try to swallow food or liquid. The doctor is talking about a PEG (gastric tube) so that you can safely get your nutrition. The doctor is unable to say whether this will be temporary or permanent.

Would you want the PEG tube?

Example 2

You have had a heart attack and your heart stopped. The medics gave you CPR and they were able to get your heart beating again, but your brain was without oxygen for many minutes. You are not waking up. After several days in the ICU, a tube was placed through your nose and into your stomach to provide nutrition.

Weeks have now passed and you have had no change in your condition. You are unconscious and the doctors are saying it is unlikely you will ever wake up. The doctors are asking your decision makers about a more permanent feeding tube (a PEG/gastric tube).

Should they agree to have the tube put in?

What if they put it in and it is now months later and you are at a long-term care facility? You are still unconscious and the doctors are saying that you are in a persistent vegetative state (you have not woken up at all and require complete care).

Should the artificial feeding continue?

Example 3

You are 93 years old. You have been in failing health for a few years. You spend most of your day in bed and you need care 24 hours a day because of your dementia. You easily forget who your friends and family are when they come to visit. You have begun to lose weight because you are not eating well. Your family and friends are worried because you are not eating and this has gone on for some time. You appear to be physically comfortable but just not interested in eating.

Would you want your doctor or decision maker to consider artificial nutrition for you?

Talk about it

What is different about the three examples?

Under what, if any, situations would you want to be artificially fed?

Is it acceptable to stop eating, knowing that without nutrition a person will die?

Notes

Dialysis (Kidney Machines)

What do the kidneys do?

The job of the kidneys is to clean waste from the blood and to get rid of extra fluid. The kidneys normally make urine, which is how the extra fluid and waste products leave the body. Dialysis is a treatment option when a person's kidneys have stopped working.

When the kidneys don't work, a person will build up too much fluid in his or her body. This can be life threatening because the fluid will move into the lungs. Another thing that happens when the kidneys don't work is that the waste products don't get removed from the body and build up in the blood. An irregular heartbeat may also develop. These conditions can cause death as well.

Potassium, magnesium and sodium are some of the chemicals that can build up and create problems when your kidneys don't work.

Kidney failure can be caused by many things. Sometimes blood pressure or blood flow problems to the kidneys can cause them to fail. Sometimes people are born with kidney problems, have diseases of the kidneys, or take medications or have accidents that injure their kidneys. When both kidneys fail, the only two treatments available are dialysis or a kidney transplant.

What is dialysis?

Dialysis is a treatment where a machine with a filter (“artificial kidney”) is used to clean the blood. The filter does the job that the kidneys would do if they were working properly. To be on dialysis, a person is hooked up to a machine three times a week for three to four hours each time. Blood is slowly pumped out of the body, through the filter, and then back into the body.

In order to be able to connect someone to a dialysis machine, he or she needs either a special temporary intravenous line (a tube into a vein) or a fistula. A fistula is something that is surgically made by connecting a person’s vein to an artery. It is created under the skin, often in the arm. The nurse puts two needles in before each dialysis treatment, one to draw blood from the person and into the filter and the other to return the blood to the person.

When otherwise healthy people develop kidney failure, dialysis is started in order to keep them alive. People can have dialysis for many years. They can work and be active, but unless they get a transplant they will need dialysis (usually three times a week) for the rest of their life.

When a person is very ill with other diseases and is hospitalized, sometimes the kidneys might fail because of these other diseases. When this happens dialysis may be considered. It is a difficult decision because while dialysis will artificially take care of the kidney problem, it will not fix the other diseases that may be making the person sick. Also, dialysis won’t cure the kidney failure; it will just keep the person from dying of kidney failure. Kidney failure itself is not painful, so the decisions are often about whether or not to start aggressive treatment to address the other diseases.

Examples

Example 1

You have food poisoning and have been very sick for several days. You are so dehydrated that your kidneys are not working well. You have a type of kidney failure that is acute (sudden) and reversible. The doctor says that you will need dialysis for several weeks, which will mean a temporary IV line and three four-hour treatments each week until your kidneys are working again. *Without dialysis you will die. Would you want dialysis?*

Example 2

You are told by your doctor that your kidneys are not working very well. You have had a history of heart disease and high blood pressure. Your doctor says that these things plus your diabetes have led to your kidneys failing. You will need dialysis three times a week for four hours each time, permanently. Your doctor says that you might be able to get on a waiting list for a transplant, but that the wait could take years. You will be able to work and enjoy your hobbies, though these activities will now need to be scheduled around the dialysis treatments. *Would you want to begin dialysis?*

Example 3

You have liver cancer that has spread to your bones and internal organs. You are very ill and it is very difficult to leave your home. You take pain medication to control the pain and that is working fairly well as long as you rest. Activity increases the pain as the cancer is in your bones. You are alert and able to enjoy visits from your friends. The doctor has told you that you will probably live about three months. A new problem has now come up and the doctor tells you that your kidneys are starting to fail. The only option is dialysis. If you choose dialysis you might live those three months, but without it your life expectancy is shorter. The doctor isn't sure how long you will live without dialysis. To get dialysis you would need to have an IV line placed in the hospital and get to the dialysis center three times a week for four hours each time. *Would you want dialysis?*

Example 4

You are a person in the intensive care unit. You have been there for more than a month. You have a severe lung infection that isn't getting better and, in fact, the infection is spreading. You now have an infection in your bloodstream and your kidneys are not working. You are on a breathing machine and you are getting artificial nutrition because you are unable to eat. You are not waking up and the doctors say that you have very little chance of survival.

Would you want dialysis started?

Talk about it

Under what situations does dialysis seem acceptable to you?

What about dialysis concerns you?

When would dialysis seem to be doing too much — going too far?

Notes

Next Steps

Additional Talking Points

Is staying alive under any condition the most important thing?

How do you feel about being kept alive no matter what?

Would there be a time when this wouldn't be acceptable?

How do you feel about living in a permanently unconscious state?

If you had dementia, but no pain or discomfort, would life-supporting treatment be OK? If not, why not? If yes, why is it OK?

Are there some situations that are worse than death to you? If so, can you describe them?

Notes

CONGRATULATIONS! You have done some very tough work. To have these discussions and focus on these issues is not easy. Some next steps to consider are as follows:

- Talk to your doctor about this work. Tell him/her what kind of things came up for you and what would be important to you if you became very ill. Having key people know more about your wishes helps to increase the chance that your wishes will be respected and honored.
- Have you picked a decision maker (durable power of attorney for health care) for yourself in case the day comes when you can't make your own decisions? If you have, perhaps he or she was involved in these discussions? If not, then tell your decision maker about your thoughts.
- Review this toolkit from time to time. Do you feel the same way? You have the right to change your mind or you may have new experiences that will change how you look at things.
- Consider putting some of your most important concerns and wishes in writing, either in a living will or on a POLST form. This will also increase the chances that your wishes will be honored.
- Remember that talking about it really does make a difference.

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