



Plan Well Guide



**Get the medical care that's
right for you**

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Getting the medical care that's right for you

To live and die well, you need to plan well.

What would be important if you or a loved one became seriously ill? Sometimes this happens over a period of time, but sometimes it happens quite quickly. Maybe you are so sick that you are unable to communicate. But there could be medical decisions that need to be made about the care you might receive, and doctors may ask your loved ones what your preferences would be. Who would speak for you? And do they know what your values and preferences are?

Often family members have a very difficult time talking about these things during a stressful time like an illness if they haven't discussed it before. We know that these topics can be difficult to discuss – but they are important.

Our planning guide is meant to help you clarify what's important to you and determine what types of medical treatments that you might or might not want in certain medical situations. When you read through the information, write down notes and questions for your doctor and loved ones. Then, you can fill out a plan at the back of this guide. It is really important that you discuss this plan with your doctors and your Substitute Decision Maker, the person who would make health care decisions for you if you were not able to do so.

Remember, you are not making medical decisions today – you are thinking about what would be important to you (or to the person you are helping) during a serious illness, based on your current health status.

This Quick Guide is a shorter version of our planning website. For more information, videos and resources to help you make your plan, please visit: www.planwellguide.com.

Serious Illness Decision Making

What is serious illness?

Serious illness is the kind of illness that requires you to be in the hospital, like a bad pneumonia or a major heart attack. You are so sick that you may die, but there is also a chance that you may recover.

You may have already thought and talked about your wishes for care at the end of your life. This guide is something different. We want to help you understand how values and preferences are an important part of decision-making about medical care during a serious illness — whether you live or die.

The role of the Substitute Decision Maker

When you are seriously ill, the doctors will speak to you and explain what is going on and how they might treat you. But most people who are seriously ill are often unable to think properly or speak. If this happens, doctors will usually turn to your Substitute Decision Maker (SDM), a person who would make health care decisions for you if you were not able to.

Often, people and their Substitute Decision Makers find it difficult to talk about serious illness decision-making. But we know that when people take the time to learn, think about and talk about their wishes for medical care, it is really helpful for them, their loved ones and the health care team. They are also more likely to get the care that matches their preferences.

Making decision about medical treatments

Sometimes when we ask people what medical treatments they would want during a serious illness, they say: "It depends. If I'm going to turn out okay, I'd want you to do everything. But if I'm not going to turn out okay, then I want you to keep me comfortable." Unfortunately, we can't predict for sure how things will turn out.

It's a bit like predicting the weather. Some days, the forecast may say there's a 50% chance of rain. You can't be sure whether it will rain or not, but you still have to decide whether you take an umbrella or a rain coat with you just in case. Or whether you stay indoors.

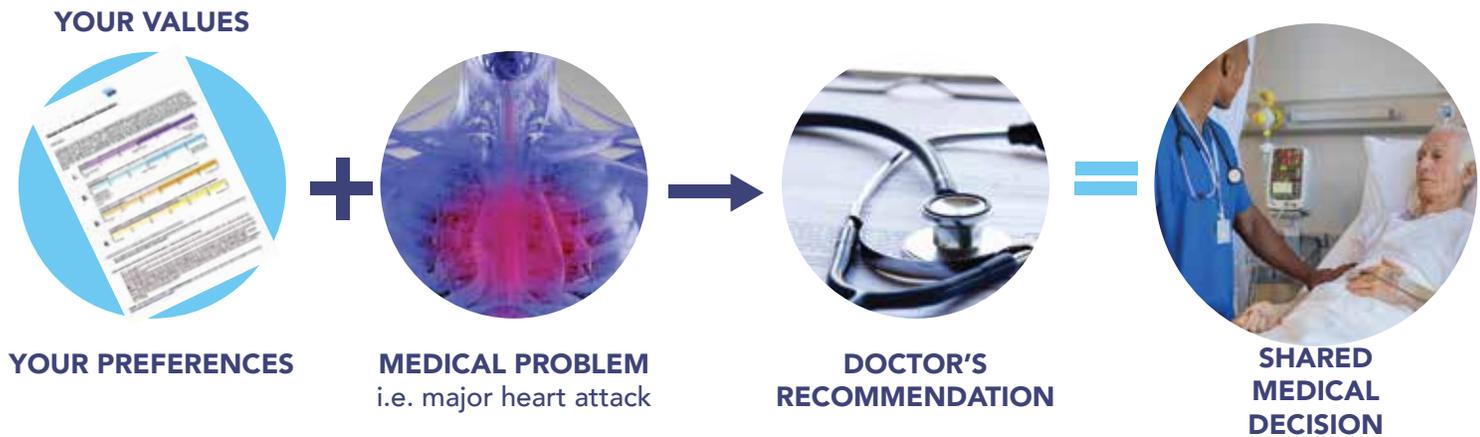
It's the same with your medical care. We don't always know in advance what might happen, so it's good to have a plan in place in case you become seriously ill, and you are unable to think and communicate. Part of this advance planning involves really being clear about what's important to you, determining your treatment preferences and communicating what things would be important to you if you had a serious illness.



It's important to remember:

Just because you want something doesn't mean you will always get it. The medical treatments you receive depend on your values and preferences, but also your illness, your doctor's recommendations, and how you are doing. Your health care team will consider your values and preferences and make decisions with you or your Substitute Decision Maker – the person you choose to speak for you if you couldn't speak for yourself.

Making Decisions with Your Doctor(s)



Thinking about your values

Values are personal feelings or beliefs that are most important to you when thinking about medical treatments that you might be offered when you are seriously ill. Your values are a big part of medical decision-making. It's not what your family thinks is important. It's not what your doctor thinks is important. It's really what you think is important.

Here are some examples of values that you may want to think about:

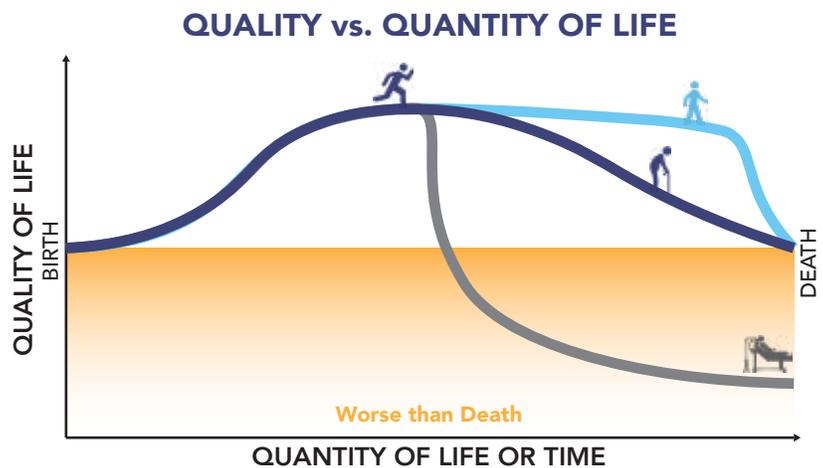
- I want to live as long as possible
- I want to avoid the use of machines in order to keep me alive if I am seriously ill
- I want to avoid symptoms such as pain and shortness of breath
- I want to live as independently as possible
- I want to continue to be able to participate in activities I like to do
- I want to be able to think clearly and not be in a constant state of confusion

Some values conflict or compete with each other

Sometimes, two things that you say are important may conflict with each other. For example, if you say, “a natural death is most important to me,” and “keep me alive at all costs,” you may not be able to have both. Keeping you alive at all costs means the health care team might have to use life-supports and other machines to keep you alive. The use of these machines will take away from you having a natural death.

You should also think about quality of life versus quantity of life. We all hope that we will live well up until the end. But that doesn’t happen very often. You may have a sudden change in health or a gradual change over time that can affect your quality of life. Sometimes, those changes can mean you end up in a condition that you may consider worse than death.

It is important for your doctor to understand which of these values is more important to you. If you value quantity of life over quality of life, doctors may use machines to keep you alive as long as possible, even if it reduces your quality of life. If you value quality of life over quantity of life, doctors may focus on treatments that maintain quality of life even if it means that you might not live as long.



Learn about Cardiopulmonary Resuscitation (CPR)

Do you know what happens when a person receives Cardiopulmonary Resuscitation, or CPR? Most people know that CPR can help people in an emergency when their heart stops, but they get a lot of wrong information from TV about how CPR works. CPR doesn’t work for everyone – and if you have a serious illness, having CPR might mean you end up getting other medical treatments that you don’t want.

If you are hospitalized with a serious illness, one of the questions you will be asked is whether you want CPR should your heart stop. If you can’t speak for yourself, the health care team will talk to your Substitute Decision Maker. If you or your Substitute Decision Maker have not have discussed CPR, or if there isn’t any information in your chart about your wishes, you may receive CPR, even if it isn’t what you would want.

Part of making your plan is making a decision about CPR in certain situations. Visit planwellguide.com to watch a video about CPR and to learn more about whether it's right for you.

Remember: there is no crystal ball. Medical doctors can’t always tell how things will turn out for you. But knowing what is important to you will help with decision making if you are seriously ill and can’t speak for yourself.

Different types of care

There are 3 main types of care that you may receive when you are seriously ill:

What is Intensive Care?



When patients need intensive care for serious illness or organ failure, they may be cared for in the Intensive Care Unit (ICU). Patients may be in the ICU because of:

- severe infection or bleeding
- breathing problems
- a bad accident
- major surgery

Along with strong medicines, there are several machines used in the ICU, including:

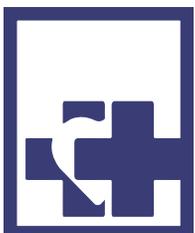
- ventilators or breathing machines
- mechanical pumps to keep the heart beating
- intravenous catheters (small plastic tubes put into big veins) that are used to provide medications
- plastic tubes placed into the stomach to provide medications and nutrition
- machines that provide cardiopulmonary resuscitation (also known as CPR)

Is ICU right for me?

Most patients recover from a serious illness when admitted to the ICU, especially if they have had a short stay. However, if you are in the ICU for some time, you may leave the hospital being much weaker than you were before you became ill and, you may have problems thinking or concentrating. Also, up to half of survivors will have significant depression, anxiety or post-traumatic stress disorder in the months that follow illness. Without intensive care, most seriously ill patients with organ failure will die. However, even with intensive care, some patients will die from their serious illness. On average, about 20% of ICU patients will die and 80% will survive and leave the hospital.

Most people who pick this option have fixable medical problems along with a reasonably high level of function or quality of life, and are willing to accept the burdens or risks of ICU treatment.

What is Medical Care?



Medical care is given in the general part of the hospital, often known as a hospital ward. People who are in a hospital ward usually have conditions such as:

- less severe infections
- problems due to an ongoing disease, such as diabetes
- mild heart attacks or strokes
- the need to recover after a surgery

Along with medications, some of the machines used to treat you in a general ward are:

- intravenous tubes (IV) to deliver medications and nutrition
- tubing to deliver oxygen but not ventilators or breathing machines
- blood pressure monitors
- specific machines for a disease, such as a dialysis machine

Is Medical Care right for me?

When admitted to hospital for medical care, most seriously ill patients recover from their serious illness and have little or no decrease in their quality of life. Approximately 70% will survive and leave the hospital alive. However, the survival rate might be higher or lower depending on the age and health condition of the patient before they got sick.

Most people who pick this option have fixable medical problems but a declining or low level of function or quality of life and wish to avoid the more burdensome ICU treatments.

What is Comfort Care?



Comfort care can be provided in a hospital, a long-term care home, a hospice, or at home. The goal is to keep you as comfortable as possible, but not to focus on curing you. For example, you may receive medications to help with pain or breathing problems, but you may not receive treatments (such as a breathing tube or CPR or even antibiotics) that would keep you alive longer, but may cause pain or make you uncomfortable. This is sometimes called a “palliative care approach” and may or may not involve services from palliative care clinicians.

Is Comfort Care right for me?

Most people who choose comfort care have serious medical problems that can’t be fixed. They may also be very old or have a poor quality of life and don’t want any treatments to help them live longer. Instead, they would rather be made comfortable.

Discussions about serious illness, death and dying can be sensitive and difficult. They can bring up strong emotions or memories. Take the time that you need to go through this information and to document your values and preferences. And then, share them with your doctor and loved ones.

Remember, to live well and to die well, you need to plan well. Don’t leave it up to fate, don’t leave it up to your family without hearing your voice, and don’t leave it up to the healthcare team to make decisions for you. Make your plan today. For more information on the different types of care, go to www.planwellguide.com/different-types-of-care/

Make Your Plan

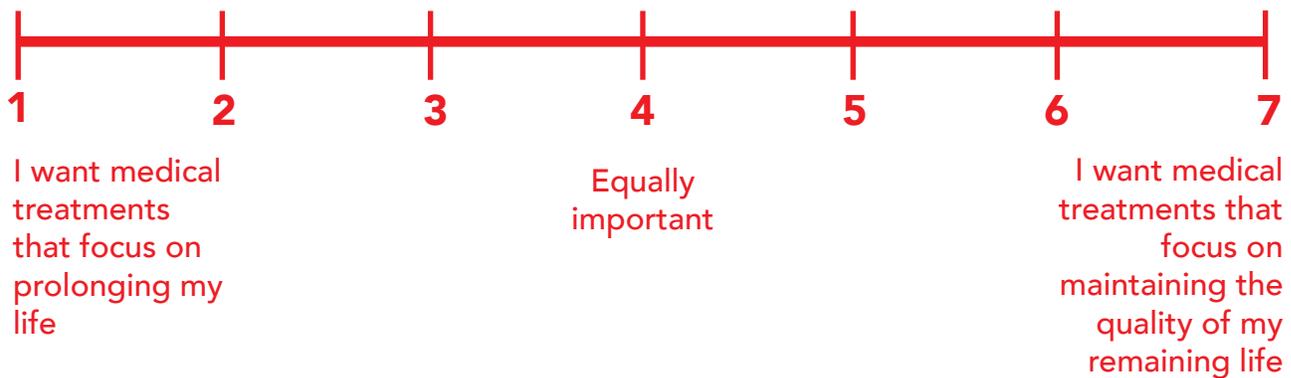
Today, given your current health state, please tell us what is most important to you when considering the treatment options for serious illness.

Remember:

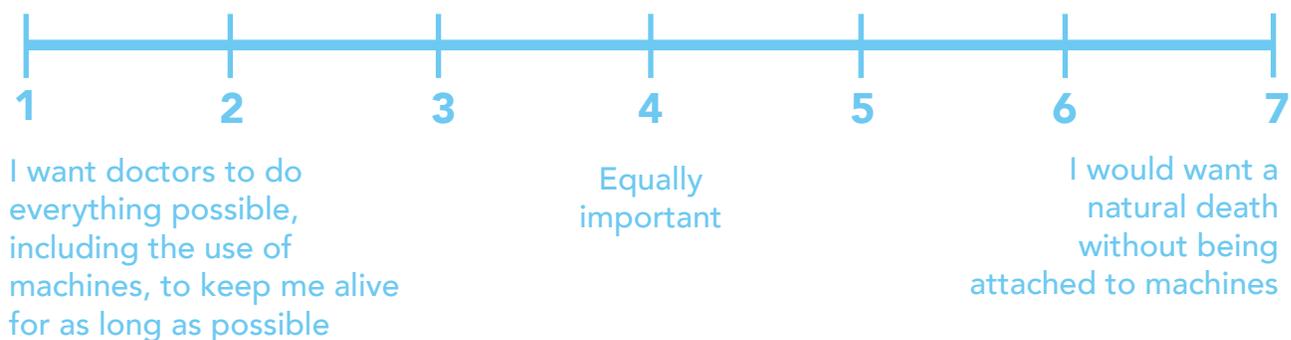
Doctors will always provide treatments to keep you as comfortable as possible, such as medications to manage pain or help with breathing.

Values Questions:

1. On a scale of 1-7 circle the number to best describe how important the following is to you:



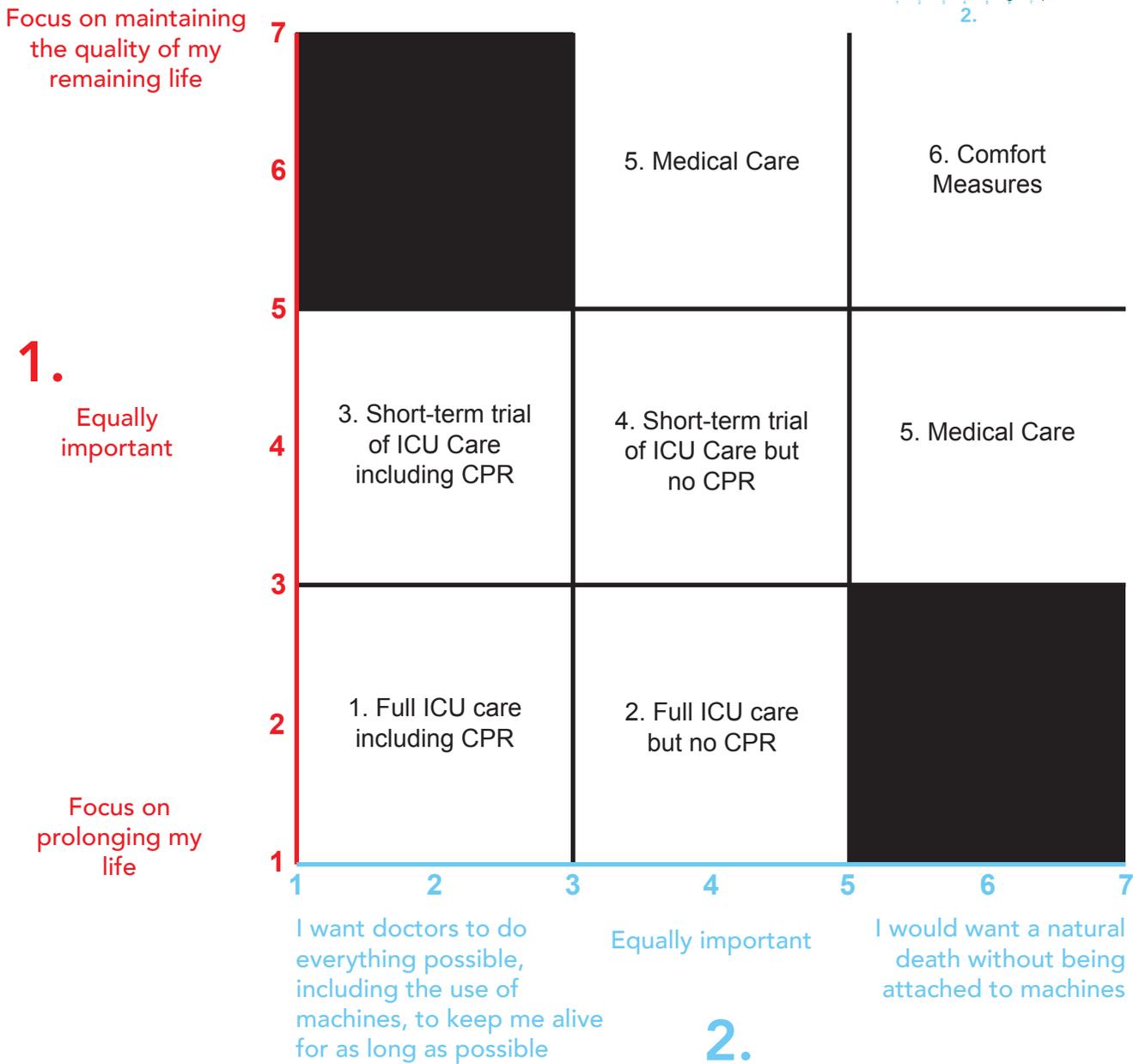
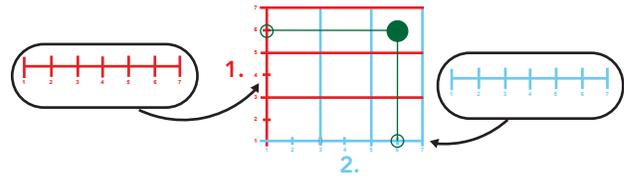
2. On a scale of 1-7 circle the number to best describe how important the following is to you:



I chose these answers because:

Which treatment options are right for you?

Take your responses from the questions you just answered on the previous page and put them on the grid below. Draw a line to the right from your answer to question 1 and another up from your answer to question 2 until they meet as shown in the small figure below. The square where your 2 answers meet will help you see what medical treatments are right for you. In each of these squares below are statements of different treatment options. Each treatment has a number beside it - look on the next page to see how the treatment matches with statements about your preferences.



There is a relationship between the answers to your values questions and the medical treatments in each of the squares. If you land on the grid in a square that suggests a medical treatment that does not match what you think is right for you, you will need to go back to the values questions and review and possibly change your answers. If you find your answers to the values questions lead to one of the 2 black boxes, your doctors won't be able to figure out which treatment is right for you so you need to go back and change your answers. If you land on the grid right between two treatments or you can't decide between two treatments, don't worry. You will have a chance to discuss this with your doctor and they will help you get what is right for you.

At this point in time, if life supports were needed to keep me alive, I prefer:

- 1. Use machines and all possible measures including admission to ICU and resuscitation (CPR) with a focus on keeping me alive at all costs.
- 2. Use machines and all possible measures including admission to ICU with a focus on keeping me alive but if my heart stops, no resuscitation (CPR).
- 3. Use machines and all possible measures including admission to ICU and CPR only in the short term to see if I will get better but if the illness is prolonged, change focus to comfort measures only. If my heart stops, no further resuscitation (CPR).
- 4. Use machines and all possible measures including admission to ICU (but no CPR) only in the short term to see if I will get better but if the illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR)
- 5. Use full medical care to prolong my life but if my heart or my breathing stops, no resuscitation (CPR) or breathing machines.
- 6. Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation (CPR).
- Unsure

As you think about the future, it is helpful to Doctors to know if there are conditions or health states that are 'worse than death.' Some people feel that being in a long-term coma or being bed-ridden in an institution dependant on others or being alive but not able to recognize family are such conditions. Please describe what you consider to be future health states that you consider to be unacceptable (or worse than death):

My Name: _____

Date: _____

My Substitute Decision Maker (SDM):

SDM's Contact Info:

Other questions or concerns I have:

Comments and Notes:

When you have finished this plan, be sure to discuss the contents with your family and your doctor. You can photocopy the last 4 pages to share with them so they have a record of your values and preferences. Your values and preferences will be really helpful to your doctors when they have to write medical orders for the use of (or not to use) life-sustaining treatments. Knowing your values and preferences will help them prescribe the treatments that are right for you!

You can update or change your values and preferences at any time. see www.planwellguide.com for electronic version of this plan or to print off another paper version of this plan.