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Pen-and-Paper Edition of the Advance Serious Illness Plan

Get the medical care that's right for you

Serious illness can happen at any time. You may become so sick that you are unable to communicate when there will be important medical decisions that need to be made about the care you receive. The doctors will look to your family members for help in making decisions that may have life and death consequences. Who would speak for you? And do they know what your values and preferences are? **If they are not aware of your values and preferences, they may suffer tremendous stress and anxiety and you may not get the medical care that is right for you.**

The sad reality is that, lots of people in hospitals today are getting medical care that isn't in line with their values and preferences because their values and preferences are not known. This adds to suffering and distress for those who need to make decisions on your behalf when you can not.

By planning your medical care in advance and sharing information with your family members, you can significantly reduce their stress and anxiety when they are called upon to make decisions for you, and you are more likely to get the medical care that is right for you!

This **simplified version** of our online *Guide to Exploring* is designed to help you begin your planning and capture the essentials of your medical care values and preferences.

To take your planning further, visit planwellguide.com to learn more about our most comprehensive planning package — the **Advance Serious Illness Planning (ASIP) Bundle**.

The Overview

Our planning guide is meant to help you clarify what is important to you (your values statements) and determine what types of medical treatments (your preferences) you may or may not want in certain medical situations based on your current health and circumstances. The last four pages of this guide is where you will complete your simplified “Advance Serious Illness Plan” (also known as the ‘Dear Doctor’ letter). As you read through the information in this guide, write down notes and questions for your current doctor (if you have one) and loved ones. There will be a place at the end of the plan to record these.

It is really important that you discuss this plan with your future doctors and your representative, the person who would make healthcare decisions for you if you were not able to do so.

Serious Illness Decision Making

Serious illness is the kind of medical condition that occurs suddenly and requires you to be in the hospital, like a serious motor vehicle accident, major heart attack or stroke. You are so sick that you may die, however there is also a chance that you may recover.

You may...

- have already thought and talked about your wishes for terminal care at the **end of your life.**
  OR
- feel that advance care planning is not important right now because you are not sick or close to the end of your life.

This is not what we are talking about. This is different. **This is serious illness planning, not end of life planning.**

At the point **when you experience a serious illness**, your future doctors will need to know whether to apply life - sustaining treatments and they may not know for sure if you are dying- so **end of life plans don't apply.** We want to help you understand how communicating your values and preferences are an important part of decision-making about your medical care during a serious illness - whether you live or die.

Making decisions with your Doctors

We are not making medical decisions today. We are preparing you today for future decisions should you become seriously ill. We do not now when serious illness might strike, it could be tomorrow or it could be 30 years from now. At that point, a doctor will try to speak to you and explain what is going on and how they might treat you. It may be your family doctor or more likely it will be an Emergency Room (ER) or Intensive Care Unit (ICU) doctor that you've never met before. They will want to know your values and preferences to help them make the decision that's right for you.

Realize that, like many things in life, we don't always get exactly what we may want or wish for.

This principle applies to serious illness planning, because the medical treatments you receive depend on a variety of factors that include, but are not limited to...

- your values and preferences,
- your illness,
- how you are doing (your prognosis),
- and your doctor's recommendations.

OUR GOAL: To help you prepare a plan that clearly communicates your values and preferences in a way that makes it more likely that you get the medical treatments that are right for you.

Your Values & Preferences + **Medical Problem** + **Doctor's Input** = **Shared Medical Decision**

The role of your representative

When you are seriously ill, your doctors will want to speak to you and explain what is going on and how they might treat you. However, most people who are seriously ill are often unable to think clearly or speak. If this happens, your doctors will usually turn to your representative, the person you have chosen to make health care decisions for you if you were not able to.

Often, people find it difficult to talk about serious illness decision-making with their representatives. We know that when people take the time to be informed, think, and talk about their wishes for medical care, it gives them peace of mind and is really helpful for them, their loved ones and the health care team. They are also more likely to get the medical care that matches their values and preferences.

Making decisions 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 to help me get better. But if I'm not then I want you to keep me comfortable."* Unfortunately, doctors 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. At the point where doctors have to decide what medical treatments to use, they won't know the outcome of your serious illness. Having a plan in place in case you become seriously ill and are unable to communicate will help. **The important part of planning is NOT about making a treatment decision, it is about being really clear on your values and preferences.**

It's important to remember: Just because you want something doesn't mean you will always get it. The medical treatments you receive will depend on your values and preferences. However, your doctor's recommendations and how you are doing will also impact your outcome. Your health care team will consider your values and preferences and make decisions with you or your representative – the person you have previously chosen to speak for you if you couldn't speak for yourself.

Thinking about your values

Your 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 the medical decision-making process. It's not what your family thinks is important. It's not what your doctor thinks is important.

Your values really express 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
- I want to avoid symptoms such as pain and shortness of breath
- I want to live as independently as possible after my medical care
- 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, the values that you say are important may conflict with each other. For example, if you say, “I want to live as independently as possible after my medical care,” as well as “I want to live as long as possible,” you may not be able to have both. Helping you live as long as possible means the health care team might have to use life- supports and other machines to treat your serious illness. However, the use of these machines could lead to a significant reduction of your independence in the months and even years following your serious illness.

You should also think about the quality of your life versus the quantity of the rest of your life (how long you will live). We all hope that we will live well up until the end. But that doesn’t happen very often.

Typically, the longer you live, the more you decline in function and the lower your quality of life may become. You may have a sudden change in health or a gradual change over time that may negatively affect your quality of life. Sometimes, these changes mean you can 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 medical treatments that maintain quality of life even if it means that you might not live as long.

What sets Plan Well Guide apart is that we help you determine and communicate your values and informed medical treatment preferences in a way that increases the chances of getting the medical treatments that are right for you. We will ask you values questions in a way that highlight the conflict between different values. We will refer to your answers to these values questions as ‘values statements’ and show you how they connect to medical treatment options. Before we go much further, let’s explain the various medical treatment options available to treat serious illness.

Three Types of Care

There are three main types of care that you may receive when you are seriously ill: intensive care, medical care, and comfort care.

Intensive Care

Medical Care

Comfort Care

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 to take over the work of the lungs
- 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

Outcomes of ICU Care

Most patients will recover from a serious illness when admitted to the ICU, especially if their stay was short. However, if patients are in the ICU for an extended period of time, such as more than 2- 3 weeks, they may leave the hospital much weaker, more so than prior to becoming ill, and they may have challenges related to thinking or concentrating.

Also, up to half of ICU 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.

Chances of Survival

On average, about 20% of ICU patients will die and 80% will survive and leave the hospital.

80% of all seriously ill patients survive to hospital discharge

The survival rate can be higher or lower, depending on specific cases – for example, if you have a severe infection, or if you are in the ICU to recover from major surgery.

60% of patients admitted with severe infection survive to hospital discharge

95% of patients admitted following elective surgery survive to hospital discharge

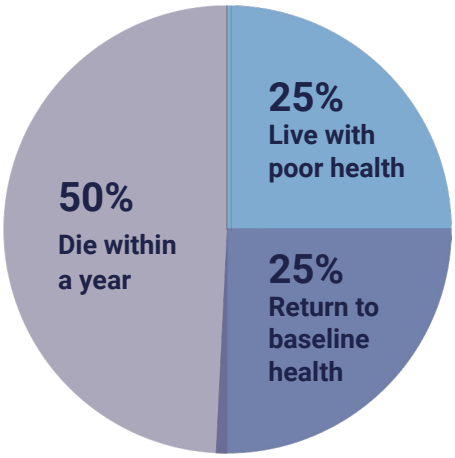
Age can also make a difference. Older patients will likely have a worse outcome than younger patients:

<80 YEARS >90% survive to hospital discharge 80+ YEARS

65% survive to hospital discharge

Overall risks and benefits of ICU Care:

One year after ICU, outcomes for patients 80+ years:



<10% Patients with previous significant medical problems will return to their baseline health

Is ICU right for me?
Most people who pick ICU care 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.

Benefits:

- If you are very ill, there is a greater chance of survival in the ICU than with other types of care.
- If you are in the ICU on machines for only a short period of time, you will likely fully recover and get back to your baseline health.

Risks:

- You may be in more pain and discomfort because of the machines used
- You may not be able to speak or interact with your loved ones
- If you are in the ICU on machines for a long time, you might end up very weak and not as mentally aware or struggle with depression, anxiety, or post traumatic stress disorder, and rehabilitation
- You may need to undergo rehabilitative treatment either on an outpatient basis or by being admitted to a rehabilitation center
- You may experience a prolonged dying experience (for example, spending 10 days on machines to finally die)

Learn about Cardiopulmonary Resuscitation (CPR)

Cardiopulmonary resuscitation or CPR is usually a part of intensive care but can be provided in other parts of the hospital as well. Cardiopulmonary resuscitation is performed to prevent immediate death in situations when a person's heart stops beating or they stop breathing. To attempt to restart the heart, the thorax must be firmly compressed, electric shocks and medication are also often used, intubation is performed to pump air into the lungs using an artificial respirator.

Cardiopulmonary resuscitation can cause complications such as rib fractures, or organs/brain injury. CPR doesn't work for everyone – out of 10 hospitalized persons on whom CPR is attempted, 1 will return to baseline health and 1 will suffer permanent brain injury. If you or your representative have not discussed CPR, or if there isn't any information in your chart about your wishes, you will probably receive CPR, even if it isn't what you would want. If you do receive CPR and survive, you will end up in the ICU and on machines for some time.

Visit planwellguide.com to watch a video about CPR and to learn more about whether it's right for you.

Medical Care

Medical care is given in the general part of the hospital, often known as a hospital ward.

People who are receiving medical care on a hospital ward usually have conditions such as:

- less severe infection
- 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

Outcomes of medical care

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

Benefits:

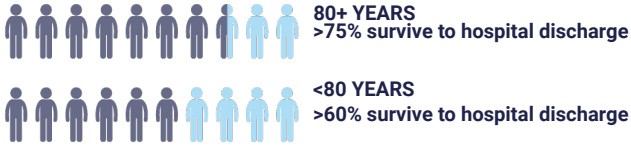
- Medical treatment can treat or cure many illnesses, which increases your chance of survival.
- Conservative medical treatments generally do not negatively impact on quality of life or comfort.
- If you do die, it will be a more natural and perhaps more peaceful death than in the ICU, as there will be fewer machines and treatments.

Risks:

- If you get worse and some of your organs are failing, you may die without ICU treatments.

Chances of survival

If you are over 80 your chances of survival are different than if you are younger.



Is Medical Care right for me?

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

Comfort Care

Comfort care focuses on managing symptoms and is sometimes called a 'palliative approach'. Most people who choose comfort care have serious medical problems that can't be cured. 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.

Comfort care can be provided in a hospital, a long-term care home, a hospice, or at home. It may or may not involve services from palliative care clinicians. **The goal is to keep you as comfortable as possible.** The focus is no longer on curing you. For example, you may receive medications to help with pain or breathing problems. You may not receive curative treatments, such as antibiotics, a breathing tube or CPR. These curative treatments would help to keep you alive longer, and may cause you pain or make you uncomfortable and are not part of comfort measures only.

Outcomes of comfort care

About 95% of patients with a serious illness who receive comfort care do not survive their illness. With comfort care they are much more likely to experience a higher quality of life at the end of their life, with a more natural death that doesn't include the use of many machines or being in the intensive care unit.

Benefits:

- Increases your chances of a natural death.
- Improves quality of life at the end of your life and you are kept as comfortable as possible.
- Because fewer technologies will be used, you are more likely to die in a location of your choice.

Risks:

- You may die more quickly.
- You may die from a disease that could have potentially been cured with a treatment, but you were not offered this treatment because you only wanted comfort care.

Chances of Survival

5% of all seriously ill patients survive to hospital discharge

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 medical treatments to help them live longer. Instead, they would rather have their care be focused on making them comfortable only, not on fixing their medical problem.

Different types of preferences for medical treatments:

The figures below introduce a range of medical treatment options available to treat serious illnesses. Review the next 2 pages before beginning to make your plan. At the end of the plan, we will ask you to pick your preferences for the medical treatments available to treat serious illnesses.

Live At All Costs

Full ICU Care + CPR

Use machines and all possible measures including admission to ICU and resuscitation (CPR) with a focus on keeping me alive at all costs.

Who typically chooses this type of care?

Usually a younger person, but can also involve an older person with no or limited health problems. People are willing to undergo prolonged critical illness with hopes of survival even if they suffer a reduction in their function or quality of life. Not for people with significant health problems, those who wouldn't want to endure a prolonged critical illness, or those who would not want any further reduction in their quality of life.

Go For It

Full ICU Care, No CPR

Use machines and all possible measures including admission to ICU with a focus on keeping me alive. If my heart stops, no resuscitation (CPR).

Similar to "Live At All Costs" but for people who would rather die than receive CPR and risk the consequence of living with some degree of brain injury from it.

Give Me A Chance

Short Term ICU + CPR

Use machines and all possible measures including admission to ICU and CPR but only in the short term to see if I will get better. If the illness is prolonged, change focus to comfort measures only and if my heart stops, no further resuscitation (CPR).

Usually a person in reasonable health or with only mild-moderate health problems. They want a chance to recover from serious illness but are not willing to put up with the downside of prolonged critical illness. They understand that they can possibly survive prolonged critical illness but enduring it only to survive in a reduced health state is not worth it to them.

For more information on the types of care available, check out our Learning Center at planwellguide.com/learn

Try For A Bit
Short Term ICU, No CPR

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. If my illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).

Who typically chooses this type of care?

Similar to “Give Me A Chance” but they too are more worried about the consequences of CPR and being alive with a brain injury than they would be with dying.

Easy Does It
Medical Care

Use full medical care to prolong my life. If my heart or my breathing stops, no resuscitation (CPR) or breathing machines.

Usually an older person or someone who is living with significant medical problems that just want conservative treatments, such as antibiotics, blood thinners, or other intravenous medications. They don’t want to go to ICU but are open to other less invasive treatments to cure them. They accept that death may be inevitable if these conservative treatments don’t work.

I Am Ready To Die
Comfort Care

Use comfort measures only with a focus on improving comfort and the quality of my remaining days. Allow natural death, no artificial prolongation of life and no resuscitation (CPR).

Usually an older person or people with advanced medical problems or terminal diseases that are not interested in any further ‘curative’ attempts. They are ‘ready to die’ when the next serious complication arises and request that all treatments focus on comfort measures only. They understand that curative treatments may be withheld and thus, they will forgo opportunities to recover from their serious illness in favour of a peaceful, comfortable death.

Anxious about finalizing your plan?

Many people get anxious and afraid to 'commit' to answers to the questions we will ask them. For example, some want a chance at recovery and yet are worried that may make a mistake asking for ICU care and end up stuck on machines forever. Others are concerned about wanting comfort care however maybe want to try medical care or ICU care if they have an illness they can most likely recover from.

Realize your answers today are not permanent, they can be changed and updated as you age and your health changes. Also, it may be helpful to discuss with your representative the nature of your anxieties as this additional information may be useful to them in the future when they are making decisions for you. If you have questions for your doctor, you can write them down on the last page of this workbook.

Note: It will be helpful to your representative and doctor if you record this fear, discuss it with them, and define, in your words, what you mean by 'short-term.' Short-term trial of ICU care is one of the treatment options in this planning guide. Later in the plan you will be given the opportunity to define health states worse than death or what health conditions are unacceptable to you.

Make Your Plan

Remember, you are not making a final medical decision today. You are preparing yourself (and your representative) to express your values statements and preferences for medical treatments should you become seriously ill. Your answers to the values and preference questions will be incorporated with your doctor's assessment of your future serious illness problem to help make a final decision that reflects your wishes. Make your plan by answering the following questions.

Given your current health, please tell us what is most important to you when considering the treatment options for serious illness. Do not think about what is important in the future when you are dying. Think about what's important *today*.

Values Questions

Reduction in Function or Quality of Life:

On the long-term, on a scale of 1-7, select the number to describe how willing you are to accept a significant reduction in your ability to look after yourself or a significantly lower quality of life following recovery from an ICU stay than you currently experience:

1	2	3	4	5	6	7

Very willing **Not willing at all**

Risks of ICU Treatments:

On the short-term, on a scale of 1-7, while in the ICU, select the number to best describe how willing you are to accept the other risks of ICU treatments/resuscitation (pain, loss of mobility or ability to talk, etc.):

1	2	3	4	5	6	7

Very willing **Not willing at all**

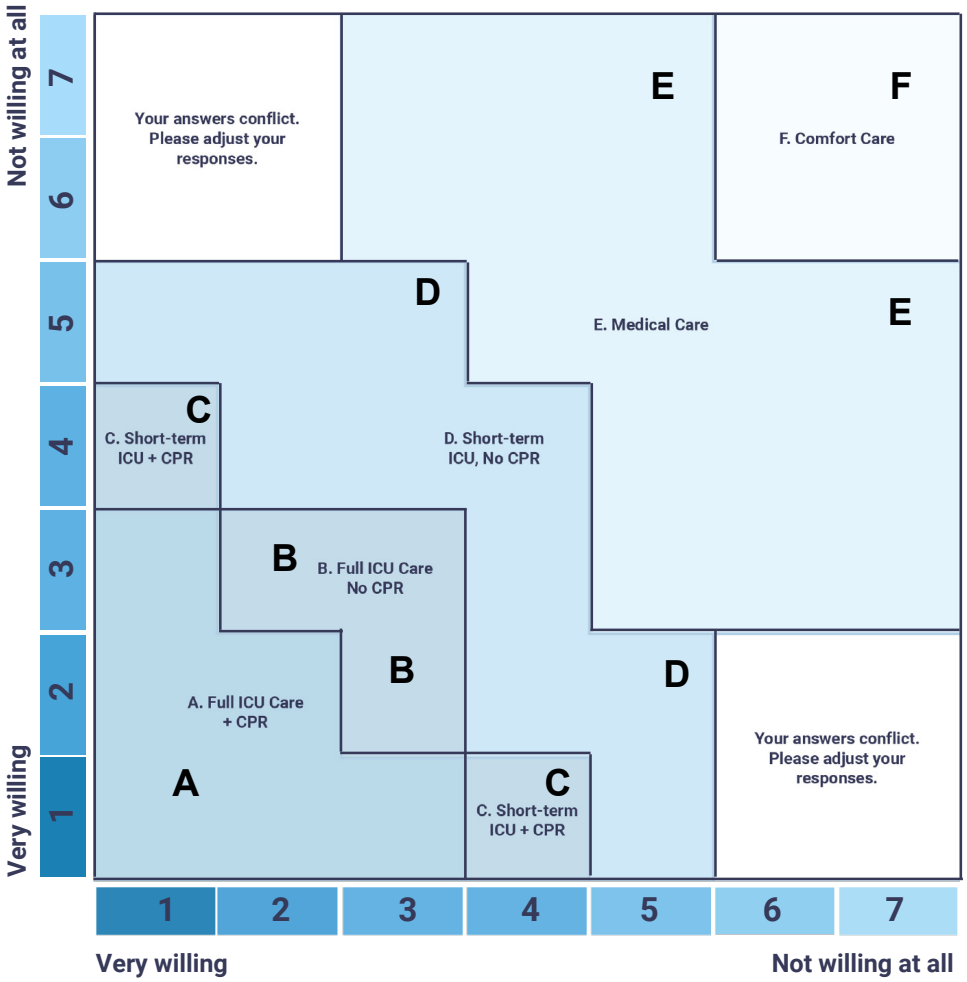
I choose these answers because:

Which treatment options are right for you?

How to find your medical treatment preference suggestion:

1. Take your answer from the first question on the previous page and circle that number on the Y-axis.
2. Take your answer from the second question and circle that number on the X-axis.
3. Find where your answers intersect, and look at the area. This area highlights the treatment option that corresponds with your answers to the values questions. For example, if you choose '3' as your answer to question #1 and '5' as your answer to question #2, at the intersection of the lines from these numbers is the cell that says "Medical Care" suggesting that this might be the right medical treatment for you when you become seriously ill.

On the long-term, on a scale of 1-7, select the number to describe how willing you are to accept a significant reduction in your ability to look after yourself or a significantly lower quality of life following recovery from an ICU stay than you currently experience



On the short-term, on a scale of 1-7, while in the ICU, select the number to best describe how willing you are to accept the other risks of ICU treatments/resuscitation

If you find your answers lead to either of the white boxes, the answers to your values questions conflict and your doctors may not be able to figure out which treatment is right for you. Please go back and change your answers to the values questions. In addition, **if you land on the grid in a cell that suggests a medical treatment that does not match what you think is right for you, please go back to the values questions to review and possibly change your answers.**

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

In each of the cells of the grid on the prior page, there was a letter and a medical treatment option highlighted. Below, you can find a longer description of each treatment option. Circle the one that you think is right for you.

A Live At All Costs **Full ICU Care + CPR**	Use machines and all possible measures including admission to ICU and resuscitation (CPR) with a focus on keeping me alive at all costs.
B Go For It **Full ICU Care, No CPR**	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).
C Give Me A Chance **Short Term ICU + CPR**	Use machines and all possible measures including admission to ICU and resuscitation CPR only in the short term to see if I will get better. If the illness is prolonged, change focus to comfort measures only. If my heart stops, no further resuscitation (CPR).
D Try For A Bit **Short Term ICU, No CPR**	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. If my illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).
E Easy Does It **Medical Care**	Use full medical care to prolong my life. If my heart or my breathing stops, no resuscitation (CPR) or breathing machines.
F I Am Ready To Die **Comfort Care**	Use comfort measures only with a focus on improving comfort and the quality of my remaining days. Allow natural death, no artificial prolongation of life and no resuscitation (CPR).

If you are having trouble determining the answers to the values and preferences questions, discuss this with your doctor and they will help you decide what is right for you.

If you chose options C or D, please describe in your own words what you mean by 'short-term':

Final thoughts

As you think about the future, it is helpful to doctors to know if there are conditions or health states that you feel are 'worse than death.' For example, some people feel that being in a long-term coma, being bed-ridden in an institution dependent on others, or being alive but not able to recognize family are such conditions. **Please describe possible future health states that you would consider to be unacceptable.**

Other questions or concerns I have:

Comments and notes:

Name:	**Date:**
Representative:	**Representative's contact info:**

You can update or change your plan at any time. You should consider updating your plan as you age or if your health or life circumstances change. See planwellguide.com for an online version of this plan or to print off another paper version.

Dear Planner,

Thank you for taking the time to read, reflect and document your values and preferences in respect to your medical care, should you become seriously ill.

As we mentioned throughout this exercise, your personal values and preferences are very important to your doctor, caregivers, family, and representative. You can photocopy the last four pages, which make up the 'Dear Doctor' letter, and share this document with them. This will help them make the RIGHT decisions concerning your medical care if cannot communicate your wishes.

Most importantly though, YOU will now have PEACE of MIND. And so will your doctors, caregivers, family and representative.

By sharing this resource with your family and friends, you can give them the gift of planning and their own peace of mind concerning their medical care should they become seriously ill.

Thank you,
Dr. Daren Heyland

Visit planwellguide.com for more of our proactive life planning tools

Our guides have been thoughtfully prepared to enhance your health and wellness so that you thrive as you age, support you and your loved ones through serious illness, and ensure you have the best possible approach to life's finish line.