

APPENDIX:

A. Feedback report



ADVANCE CARE Planning

Personal Health Report for Advance Care Planning

What is Advance Care Planning?

- Taking control of your own health care – getting your medical house in order– taking the burden off of your loved ones.
- To do this, you can:
 - Decide how you feel about things like the use of machines to prolong life.
 - Put a plan in place, so that you can get the kind of care you want.

What are the Steps of Advance Care Planning?

- Fill out two forms: a living will and a health care proxy.
- Talk to people close to you, especially your proxy, about your wishes and values.
- Talk to your doctor about your wishes and give your doctor copies of your forms.

Why do I need to do Advance Care Planning?

- While most of us hope to die in our sleep, the fact is that people can get sick in unexpected ways that need hard decisions to be made.
- When people get very sick, they often cannot make or state their own decisions.

But what if it is too hard to think about getting very sick and dying?

- If you don't make an Advance Care Plan, your loved ones may have a harder time making decisions for you.
- Making an Advance Care Plan can take the burden off of your loved ones.
- You can do this in small steps. Many people find that doing this isn't as bad as they imagined.

Now here are some suggestions just for you based on what you told us about how ready you are to take the next steps.

Living Will - How ready are you?

Since you are not ready to complete a living will, here are a few simple things you can do:

- Spend 5-10 minutes reading through and thinking about the first booklet.
- You don't have to do it all at once.
- You can take a break and come back to it. (Just don't put it off for too long.)
- If you are worried about putting your wishes down in writing, remember that you can change your mind at any time.

Since you have already talked to a loved one about how you think about quality versus quantity of life, you have already thought about the wishes that you will want to write down in your living will. Completing the living will gives your loved ones and your doctor(s) a written record of your wishes.

Health Care Proxy - How ready are you?

Since you are not ready to think about choosing a health care proxy, here are some things you can consider:

- Spend 5 to 10 minutes thinking about who might be a good proxy for you. Then, in a few days, think about this choice again.
- Remember that it's not as hard as you might think to bring up the topic of Advance Care Planning with a proxy. You can do this in small steps. You can ask someone to be your proxy now as a first step. Then, you can plan to talk about hard decisions later.
- Remember that choosing a proxy can help to prevent fighting in the family if you have more than one person who might want to make decisions for you.

Since you have already talked to a loved one about how you think about quality versus quantity of life, this person may be your best choice as a health care proxy.

- You can remind this person of your conversations and ask if he/she would be your health care proxy.
- Completing the form will make sure that the doctors go to this person if a healthcare decision needs to be made for you.

Talking about your Values- How ready are you?

You have already spoken to people close to you about your needs and wishes for future health care. This is great! Here are some things to keep in mind:

- Take a look at the questions on page 8 of the 2nd booklet. Think about whether your conversations with your loved ones included all of these topics.
- If anything changes, look at these questions again to see if your wishes have changed. If so, then you may need to re-write your living will and have another discussion with your loved ones and your proxy. Make sure you update your doctors too!

Talking with your Doctor- How ready are you?

Since you are not ready to talk to your doctor(s) yet, here are some simple things you can do to make progress:

- Don't assume the doctor already knows how you feel. If the doctor doesn't know, then he/she cannot make decisions that honor your wishes.
- Remember that, although the doctor may seem rushed, he/she will probably be very happy if you raise this topic.
- Remind yourself how important it is that your doctor knows how you feel about these things.

How Advance Care Planning Can Help You

You may not realize all of the benefits of an Advance Care Plan. People who have an Advance Care Plan:

- Feel good about being responsible by taking care of their future.
- Know that they are helping to reduce the burden on their loved ones.
- Have the peace of mind that comes with planning ahead of an emergency.
- Feel more secure knowing that they will get care that they would want, no matter what happens.
- Feel relief that they have taken care of a difficult issue.
- Know that they are in control of the care they will receive in the future.

Overcoming Reasons Why Advance Care Planning Can Be Hard

There can be many reasons why it can be hard to think about making an Advance Care Plan:

- Many people don't like thinking about becoming sick.
- Some people hope they won't need to make hard decisions.
- Some people think there are too many choices or worry that they might change their minds.
- For some people, talking to their loved ones is hard.

Here are some ways to help make thinking about this easier:

- You can remind yourself and your loved ones that planning now will make things a lot easier in the long run.
- Once you have made a plan, you don't have to think about this again until something changes.
- You can do planning in small steps. Doing a few small steps can be easier than trying to do it all at once.
- You can read through the first booklet for more answers to concerns you may have. This booklet also has stories of other peoples' experiences with Advance Care Planning. These stories show that Advance Care Planning can be hard. But they also show how making a plan can really help give you and your loved ones' peace of mind.

Your Values & Beliefs

Here are some beliefs that you said you agreed with (shown in bold) followed by a few more ideas to think about that may be useful for your decision making.

Your future is in the hands of God.

If you believe that God has certain plans for you, then it is even more important for you to create an Advance Care Plan. It is important for your doctors and your loved ones to understand what you believe God's plans are. If you want to be kept alive in order to see if a miracle will occur, it is important that your doctors know this. How long will you wait? Would anything affect your choice to wait? Is your doctor in agreement with this?

Thinking about future bad things makes them more likely to happen.

Unfortunately, bad things can happen to all of us whether or not we think of them ahead of time. It may be that, just like carrying an umbrella and then not having it rain, making an Advance Care Plan could mean that you and your loved ones will not have to face a hard decision in the future. However, avoiding advance care planning won't protect you from getting sick at some point down the road.

Your Summary

Thank you for reading this report about Advance Care Planning and how it can help you. We hope you have found some support and some new ideas in this report. The pamphlets have more information and stories for you. When you're ready, taking some of your next steps towards Advance Care Planning can help you take control of your medical care and take care of your loved ones at the same time.

B. Brochure



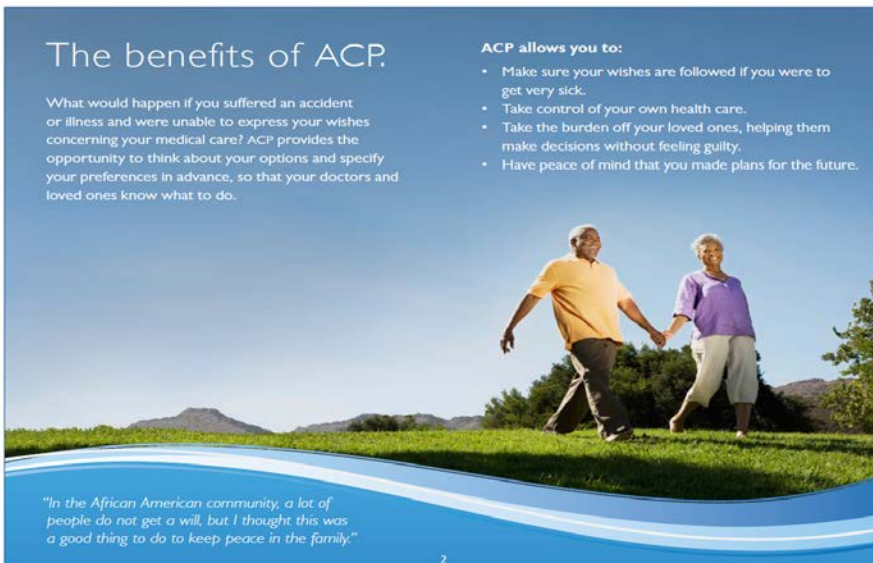
Your Life, Your Values, Your Choices
Putting Your Health Care House In Order

Participating In Advance Care Planning: Part I

Yale SCHOOL OF MEDICINE

THE UNIVERSITY OF RHODE ISLAND

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The benefits of ACP.

What would happen if you suffered an accident or illness and were unable to express your wishes concerning your medical care? ACP provides the opportunity to think about your options and specify your preferences in advance, so that your doctors and loved ones know what to do.

ACP allows you to:

- Make sure your wishes are followed if you were to get very sick.
- Take control of your own health care.
- Take the burden off your loved ones, helping them make decisions without feeling guilty.
- Have peace of mind that you made plans for the future.

"In the African American community, a lot of people do not get a will, but I thought this was a good thing to do to keep peace in the family."

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