Patient Education
intermountainhealth.org

Making Choices®

Advance Care Planning Workbook

Intermountain Health

What's Inside:

Respecting Choices®
PERSON-CENTERED CARE

Peace of mind comes from preparedness

There may be a time when you are unable to make your own medical decisions because of a serious illness or injury. In these moments, someone else will have to make medical decisions for you.

Intermountain Health has created this tool to help you organize your thoughts and then share them with your providers, family, and friends. It is not a test and there are no right or wrong answers. Your answers will help your loved ones make choices for you if you are too sick to decide for yourself.

You might not think you need to make these plans now. But it is important to begin planning early. People often feel it is too soon until it is too late.

Take your time and read through this booklet and write down your questions. You don't have to make all these decisions at once, but this is a good place to start.

Intermountain Health

Step 1: Who will speak for you?

An important part of planning is choosing who should make your medical decisions if you can't make them yourself. This person is a called a **healthcare agent**. Many people choose a close family member, but you can pick anyone who is 18 or older. You need to be able to trust this person to be:

- Willing to accept this responsibility.
- Willing to talk to you about what matters most.
- Willing to follow your instructions you have discussed and written down.
- Able to make difficult decisions.

Preparing your healthcare agent

Your healthcare agent needs to understand your wishes for future medical care and what matters most to you. **The best ways to do this are:**

- Invite your healthcare agent to your doctor appointments
- Let your healthcare agent ask you questions about your wishes
- Sit down and talk about your medical wishes

Use this worksheet to help you determine what matters most to you.

Things to consider when choosing a healthcare agent

The person you choose to be your healthcare agent must be:

- Willing to take on this role and responsibility.
- Willing to talk with you about the healthcare you want or don't want if you have a serious injury or illness.
- Able to follow through on your healthcare decisions even if they do not agree with your choices.
- Able to make these medical decisions in difficult and often stressful situations.

Step 2: What matters most to you?

Your current health

1 **Do you have any health problems right now?** (Example: diabetes, COPD, rheumatoid arthritis, kidney disease, others): _____

2 **What worries you about your health problems?** _____

3 **What health problems do I fear in the future?** (Example: "My mom has heart disease. I worry I will develop that.") _____

Your healthcare experiences

1 **Think about a time when you were in the hospital. What went well?** _____

2 **What would you change?** _____

3 **Think about a time when a family member or friend was in the hospital or had to make a big medical decision. What was good about that time? What went well?** _____

4 **What do you wish was different?** _____

5 **What would you want if you were in the same situation?** _____

Your values and beliefs

1 **What kinds of things bring you joy?** _____

2 **If a health problem kept you from doing them, how would your life's meaning change?** _____

3 **How would you like your culture included in your medication care?** (Example: "I believe in hot and cold therapy" or "Please direct questions to my grandmother, she is the matriarch of my family".)

4 **How does your religion, faith, spirituality, or other belief systems influence how you make medical decisions? Accept medical care?** _____

5 **Based on your answers above, what will help you live well right now?** (Example: "Because I love to cook, I want to sign up for a cooking class while I still can" or "Because spirituality is so important to me, I need to make an appointment with my spiritual care advisor to discuss my needs".)

What else is important for your healthcare agent to know about you?

Worksheet:
What does my healthcare agent need to know about me?

These scales might help you think about how you like to make decisions and how you prefer your medical information to be shared.

1 = not important 10 = very important

I like to know:

All the details about my condition and treatments

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

As doctors treat me, I would like:

To have a say in every decision

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

If I had an illness that was going to shorten my life, I prefer to:

Not know how quickly it is likely to progress

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

Pain control:

I want to avoid pain and suffering, even if it means I might die sooner

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

Alertness:

I want to be able to talk with those around me, even if it means I experience pain

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

Environment:

I want to be able to feel someone touching me

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

If possible, I want to die at home

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

Other:

I want to be able to tell my life story and leave good memories for others

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

I want to be able to reconcile any differences and say goodbye to family and friends

O O O O O O O O O O
1 2 3 4 5 6 7 8 9 10

Step 3: Choosing Your Care

Your care

It is important to plan for a time when you:

- Suddenly become unable to make your own decisions.
- Will clearly have little or no recovery.
- Have a significant injury or loss of function.

These things might be caused by a brain injury or a slowly developing disease like Alzheimer's. To plan for these things, many people say:

- "If I'm going to be a vegetable, let me go."
- "No heroics."
- "Don't keep me alive on machines."

While these statements are a start, they are unclear to your healthcare agent and care team. You need to describe when it makes sense to change from prolonging life to allowing a natural death. The following questions and scenarios will help you paint a clear picture for your healthcare agent and care team.

Examples of treatment and care options can include:

- **Surgery**
- **Dialysis**
- **Antibiotics**
- **Oxygen support**
- **Pain management**
- **Blood product transfusions**
- **Chemo therapy or radiation therapy**
- **Short- and long-term artificial nutrition** (feeding tube)
- **Intubation** (breathing tube attached to a ventilator machine—requires treatment in the ICU)
- **Rehabilitation services** (physical therapy, occupational therapy, speech therapy, short-term care in a nursing home)

1 **Which of these treatment options would you consider?** (Circle those above that you would choose)

2 **What treatments do you want that are not listed?** _____

3 **When would it make sense to stop or withhold certain treatments, and accept a natural death when it comes?**
For example: "If I had to be on a breathing machine for the rest of my life" or "If I would know who I was or know those around me if I woke up". _____

4 **Do the goals you listed in the "What Matter Most to Me" worksheet above, match with what you would choose for continuing and stopping treatments in question #1?**
If no, what would be a goal that matches what matters most to you? _____

5 **Would the cost of treatment influence your decision for care?** If yes, why? _____

Time trials

You might want to try some treatments for a short time to see if they help. You can change your mind at any time by telling your healthcare agent to stop treatment and allow a natural death. Here are some examples of how a trial period can be worded in your advance directive.

- "I am willing to try artificial nutrition for 4 weeks. If after 4 weeks my doctor does not feel I have made any progress and will not with further treatment, then I choose to stop artificial nutrition and allow for a natural death."
- "I am willing to try intubation for 2 weeks. If after the trial period I have not improved, then I choose to have my healthcare agent stop my intubation and allow for a natural death."

Examples to consider

On this page and the next are examples of injuries, illness, or treatments that you might face in the future. Consider what care you would want in each situation.

Permanent brain damage

I have a serious complication from an accident or illness. I have a good chance of living through this complication. It is likely that I would never know who I was or who I was with, and would require 24-hour nursing care. In this situation, I would choose the following: (Whatever my choice, I want to be kept as comfortable as possible)

☐ **To continue all treatment so I could live as long as possible. The goal is to prolong life by all medically effective means.** Although staying alive is important to me, I would want to stop treatment if any of the following unacceptable outcomes occur (length of time on machines, inability to manage symptoms, etc.):

_____

☐ **To stop all efforts to keep me alive.** The goal is to maximize comfort and allow a natural death.

Permanent physical disability

I have a serious complication from my accident or illness, and have a good chance of living through this complication. It is likely that I would not be able to either walk or talk (or both) again. I would require 24-hour nursing care. In this case, I would choose the following: (Whatever my choice, I want to kept as comfortable as possible)

☐ **To continue all treatment so I could live as long as possible. The goal is to prolong life by all medically effective means.** Although staying alive is important to me, I would want to stop treatment if any of the following unacceptable outcomes occur (length of time on machines, inability to manage symptoms, etc.):

_____

☐ **To stop all efforts to keep me alive.** The goal is to maximize comfort and allow a natural death.

Prolonged hospital stay

I have a serious complication from my illness (or treatment for my illness). I am facing a long-term hospital stay, requiring ongoing medical care, AND my chance of living through this complication is low (for example, only 5 out of 100 patients will live). In this case, I would choose the following: (Whatever my choice, I want to be kept as comfortable as possible)

☐ **To continue all treatment so I could live as long as possible. The goal is to prolong life by all medically effective means.** Although staying alive is important to me, I would want to stop treatment if any of the following unacceptable outcomes occur (length of time on machines, inability to manage symptoms, etc.):

_____

☐ **To stop all efforts to keep me alive. The goal is to maximize comfort and allow a natural death.** A low chance of survival to me is:

_____

Treatment options for CPR and breathing to consider

CPR: If I have a sudden event that causes my heart and breathing to stop, I would choose the following:

☐ **To have CPR attempted unless my physician determines either of the following:**

- I have an incurable illness/injury and am dying
- CPR could harm me more than help me.

☐ **To not have CPR attempted if my heart stops,** allowing for a natural death.

Breathing: If I have an event where I am unable to breathe on my own, I would choose the following:

☐ **To attempt to use any appropriate noninvasive method (**like a mask) to assist my breathing; if this method fails:

- Use mechanical ventilation, OR
- Do not use mechanical ventilation. To not attempt to assist my breathing by non-invasive methods or mechanical ventilation, allowing for a natural death.

☐ **Do not attempt to assist my breathing by** non invasive means or mechanical ventilation, allowing for a natural death.

Step 4: Documenting Your Care Decisions

It is important that you write down your wishes and that they are clear and detailed. Your wishes are best written on your state's **advance directive for healthcare.** (See Step 5 for a link to get your state's advance directive document). Before filling out your advance directive, describe what some commonly used phrases mean to you. In the table on the next page, we give some examples of unclear statements and better word options.

1 **You may have heard people use the term "being a vegetable". How would you describe this term to your healthcare agent?** _____

_____

_____

2 **How do you describe "heroic measures"?** _____

_____

_____

What heroic measures would you want? _____

_____

_____

What heroic measures do you **not** want? _____

_____

_____

3 **How do you define "being a burden"?** _____

_____

_____

Unclear or vague	More specific or clear
I don't want to be a "vegetable."	• I don't want medical care to continue if I will not know who I am or who I am with.
I don't want any "heroic measures."	• If I will not wake up and know who I am or who I am with, I want you to stop medical treatment allowing for a natural death. • If I am found without a heartbeat or not breathing, I do not want to be resuscitated.
I don't want to "be a burden."	• I don't want to create a large medical bill for my family. I would prefer to have a natural death". • I don't want to have my spouse or children change their lifestyle to take care of me. I would prefer to stop treatment and allow for a natural death. • If I cannot feed or bathe myself (or both), I would prefer to stop treatment and allow for a natural death.

Step 5: Sharing Your Decisions

Now that you've thought about your care and written down your decisions, it's time to:

1. Talk about your feelings and choices with your family, friends, spiritual care leaders, and doctors.
2. Put your choices in writing. Use your state's form. Click the link below to find your state's advance directive for healthcare form or copy and paste this address into your web browser: https://intermountainhealthcare.org/health-information/advance-directive
3. Give copies to all of your doctors, healthcare facilities, your healthcare agent and those you want to share your wishes with.
4. Submit your forms to Intermountain Health so they are in your electronic medical record.

Utah and Idaho

Mail: Intermountain Health Advance Directive
PO Box 571069 Murray, UT 84157

Fax: Using the original form fax to: 801-903-1619

Email: Scan all the pages of your form and send to: advancedirective@r1rcm.com

All other states

In-person: Take a copy of your advance care planning documents to your primary healthcare provider's office.

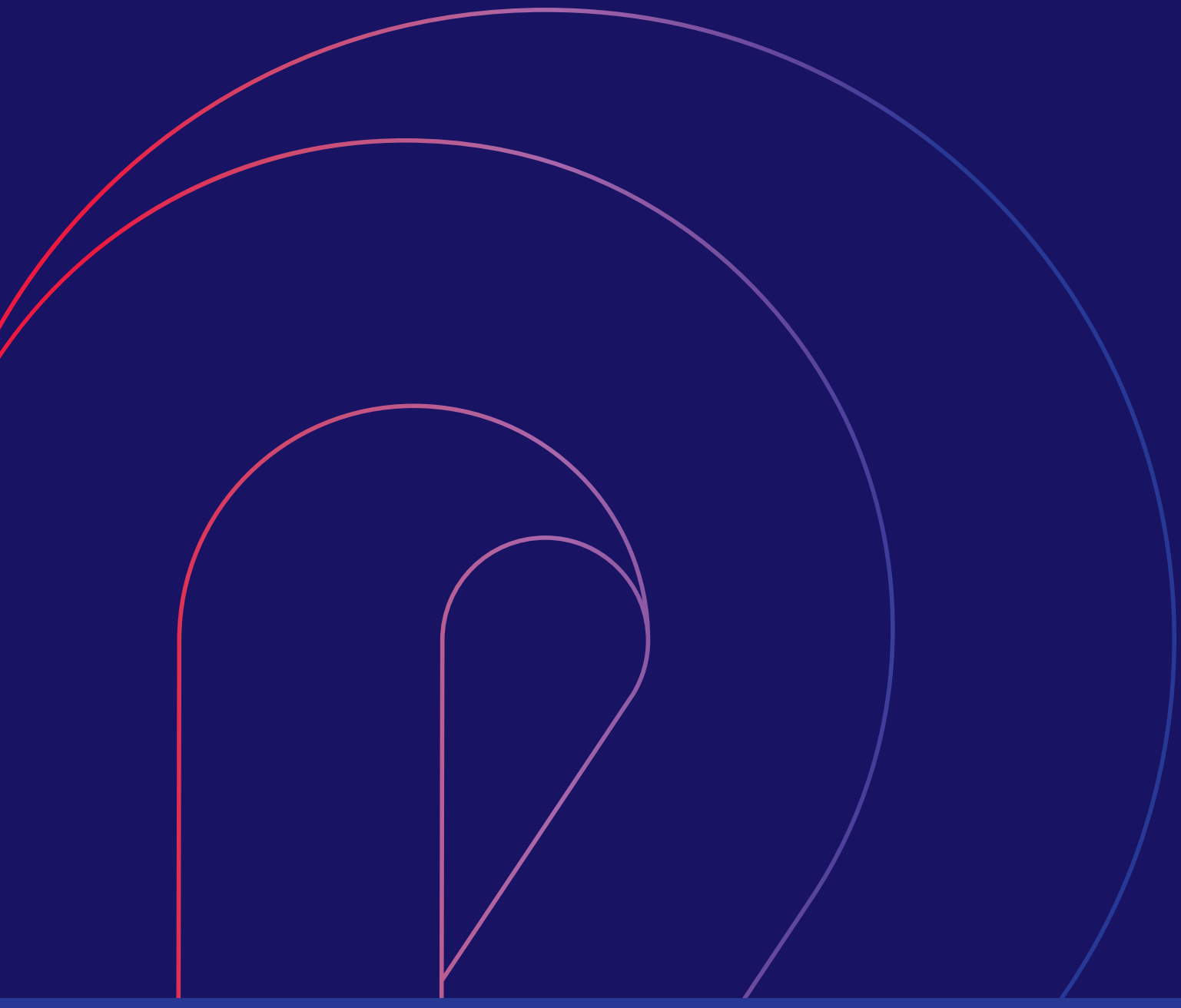
FREE advance care learning sessions

For more information on advance care planning join us virtually for one of our FREE sessions to learn more.

1. Scan the QR code below with your phone camera.
2. Click on the link that appears on your phone's screen.
3. Choose the date/time you want to attend.
4. Register.

You will receive an email with instructions on how to join.

To find this booklet and other patient education, go to:
intermountainhealth.org



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