Are You Traveling Without a Map?  
A Layperson’s Guide to Advance Care Planning

Katherine Brandt, MS, Vice President, Consumer and Caregiver Services, National Hospice and Palliative Care Organization

Advance care planning is like planning a road trip to an unfamiliar destination. If you’re like many people, once you have your destination in mind you begin mapping the route you will take to get there. Some people consult AAA or Google Maps to help them chart their course. Other people talk to friends and family members about their experiences regarding their previous trips.

While people approach mapping their route in differing ways, very few people would expect to arrive at their destination safely and comfortably without having a well-thought out map in hand before hitting the road. Yet only 30% of American’s have a living will, a map detailing where they want their health care to “go” in the future should they become unable to voice their wishes.

Map Your Journey

A living will charts the course for your health care, letting your family and health care providers know what procedures and treatments you would want provided to you — and under what conditions. If you’re one of the 70% of Americans without a living will, it’s best not to wait to chart the course for your future health care. Without a map, your health care journey is out of your hands and may not take you in a direction you’re comfortable with.

What if you have a sudden, serious illness or accident and you’re unable to breathe on your own, would you want a tube to be placed in your throat to push air into and out of your lungs? If you are diagnosed with an illness that your doctor thinks is incurable and likely to shorten your life significantly, do you want the focus of your care to be on keeping you comfortable and pain free? Or do you want a combination of life-extending care and comfort care? A living will, like a route marked on a map, indicates which direction you’d like to take at each fork in the road. It’s your journey — you decide which roads you want to take and when.

Choose a Back-up Driver

A health care power of attorney or health care proxy designation form, the second type of advance directive, allows you to choose someone you trust to “drive” (take charge of your health care decisions) in case you are unable to make those decisions yourself. You might want to pick a family member or friend who is comfortable talking to doctors.

If you don’t decide who can “drive” and you end up unconscious you might end up being taken on a health care journey that is contrary to your values, wishes, and choices. Choose someone you trust to be your back-up driver so that when unexpected road blocks appear along your health care journey, your back-up driver is able to choose a detour that is in keeping with your values, wishes, and choices. Your health care journey may involve traveling long distances, so prepare your back-up driver by reviewing your map with and allowing them to ask questions so they are prepared when it is their turn to drive.

To learn more about advance care planning, including living wills, health care proxy and talking to people about your wishes explore the planning ahead section of www.caringinfo.org or call 800-658-8898.
Update Your Map and Make Sure Your Driver is Prepared

Just as your travel preferences might change as you age, so might your living will. Your first living will might state that you want all care focused on sustaining your life and at some point later in your life you might change your mind. Later on you might decide your priority is to try life-extending treatment for a period of time and then transition to a focus on comfort care. And at some point, you may or may not choose strictly comfort care, like hospice, to allow for a natural death in the setting of your choice with friends and family around you. Therefore, as your preferences change, it’s essential that you update your living will, and that you make sure your backup driver knows what you want.

In the end, the route you take and the driver you pick are your choices to make. And the care you receive and who talks to doctors on your behalf is also your choice, but only if you make a plan now.

What is Advance Care Planning?

Advance care planning involves...

- Understanding your possible future health care choices.
- Thinking about your choices in light of what is important to you and your values.
- Talking about your decisions with loved ones and your doctors.
- Writing down your plans in advance directives so they will be ready if needed.

It’s important to remember that...

- Your plans and advance directives can be changed as your situation or wishes change.
- Advance care planning is done over time and not a single conversation.
- Decisions like these are best considered before there is a health crisis — and changes to your plans can be made at any time.
- Planning ahead for your health care — now, while you are able to — is a gift you can give to yourself and those you love.

Caring Connections Advance Care Planning Resources:

- State-specific advance directive forms
- Understanding Advance Directives
- End-of-Life Decisions
- Leaving a Legacy
- Saying Goodbye
- Conversations Before the Crisis
- If You or Someone You Love is Very Ill...Ask Tough Questions
- Artificial Nutrition and Hydration at the End of Life
- Communicating End-of-Life Wishes

For more information, or to download an advance directive form or brochure, visit: www.caringinfo.org/planningahead