

PASSING ON

A RESOURCE GUIDE

ARIZONA
PUBLIC MEDIA



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Death is as much a part of human existence as is life, yet it remains a mysterious and often taboo subject. The Arizona Public Media (AZPM) original documentary *Passing On* explores death and dying through a series of compelling, personal and thought provoking stories that will engage viewers and provide valuable information about planning for end of life.

According to a national survey by The Conversation Project, 90 percent of people say that talking with their loved ones about end-of-life care is important, but only 27 percent have actually done so. Sixty percent of people say it is important to them to make sure their family is not burdened by tough decisions that come up during end of life situations, yet 56 percent have not communicated their wishes.

In partnership with the Pima Council on Aging (PCOA), we have created this complementary guide to accompany *Passing On* as a resource for members of the community to make informed end-of-life decisions. In it you will find frequently asked questions, key terms and definitions, tips for how to get started, information about long-term care, sources for legal and medical documents and forms, as well as legacy and end-of-life planning.

We hope that this guide, while providing valuable information will also offer some peace of mind in preparing for end of life issues when they arise in your own family.

END OF LIFE CARE: MAKING A PLAN

Why is planning for your end of life care important?

- By planning, you make decisions that reflect your wishes for end of life care and create a guide for loved ones and health care professionals to follow.
- By not planning, you allow others to make decisions for you.
- By planning, you provide your loved ones with peace of mind because they will know what you want and will not be left guessing.

Key Concepts

- Think about what is important to you and what care you want at the end of your life. Professionals or family members can help you with this.
- Document your wishes by creating an advance directive.
- Communicate your wishes to family members, friends and health care professionals by sharing copies of your advance directives. Note: If life circumstances change, plans can be changed.

Key Terms

Advance directive: instructions about what kind of care you want and don't want and who can speak for you if you are not able to express your wishes.

Living will: also called a directive to physicians or advance directive, is a document that lets people state their wishes for end-of-life medical care, in case they become unable to communicate their decisions. It has no power after death.

Health care power of attorney and mental health care power of attorney: who you designate to speak on your behalf if you are not able to speak for yourself

What forms do I need to fill out?

Each state has its own requirements for making end of life care wishes official. In Arizona, you can complete official forms or write out a personal statement of your own. In either case, your documents need to be properly signed and witnessed.

Where can I get forms or planning documents?

Please visit passing-on.org for additional End of Life Care resources including:

- Life Care Planning forms from the Arizona Attorney General
- Aging with Dignity: Five Wishes workbook
- The Conversation Project: Conversation Starter Kit
- Compassion and Choices: Good-to-Go Toolkit
- Elder Guru's Your Life, Your Choices workbook



Sharing your wishes for end-of-life care can bring you closer to the people you love. It's critically important. And you can do it.

Consider the facts:

90%

of people say that talking with their loved ones about end-of-life care is important.

27%

have actually done so.

Source: The Conversation Project National Survey (2013)

60%

of people say that making sure their family is not burdened by tough decisions is extremely important.

56%

have not communicated their end-of life wishes.

80%

of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.

7%

report having had this conversation with their doctor.

82%

of people say it's important to put their wishes in writing.

23%

have actually done it.

Source: Survey of Californians by the California Health Care Foundation (2012)

STEP 1: *Get Ready*

You will have many questions as you get ready for the conversation.

Here are two to help you get started:

What do you need to think about or do before you feel ready to have the conversation?



Do you have any particular concerns that you want to be sure to talk about?

For example, making sure finances are in order; or making sure a particular family member is taken care of.



STEP 2: Get Set

What's most important to you as you think about how you want to live at the end of your life? What do you value most?

Thinking about this will help you get ready to have the conversation.

**Now finish this sentence:
What matters to me at the end of life is...**

(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

Sharing your "what matters to me" statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

WHERE I STAND SCALES

Use the scales below to figure out how you want your end-of-life care to be. Select the number that best represents your feelings on the given scenario.

As a patient, I'd like to know...

- 1** **2** **3** **4** **5**
- Only the basics about my condition and my treatment
- All the details about my condition and my treatment

As doctors treat me, I would like...

- 1** **2** **3** **4** **5**
- My doctors to do what they think is best
- To have a say in every decision

If I had a terminal illness, I would prefer to...

- 1** **2** **3** **4** **5**

Not know how quickly
it is progressing

Know my doctors best
estimation for how
long I have to live

Look at your answers. What kind of role do you want to have in the decision-making process?

How long do you want to receive medical care?

- 1** **2** **3** **4** **5**

Indefinitely, no matter
how uncomfortable
treatments are

Quality of life is
more important to
me than quantity

What are your concerns about treatment?

- 1** **2** **3** **4** **5**

I'm worried that I won't
get enough care

I'm worried that I'll get
overly aggressive care

What are your preferences about where you want to be?

- 1** **2** **3** **4** **5**

I wouldn't mind spending my
last days in a health care facility

I want to spend my
last days at home

Look at your answers. What do you notice about the kind of care you want to receive?

How involved do you want your loved ones to be?

1 2 3 4 5

I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable

I want my loved ones to do what brings them peace, even if it goes against what I've said

When it comes to your privacy...

1 2 3 4 5

When the time comes, I want to be alone

I want to be surrounded by my loved ones

When it comes to sharing information...

1 2 3 4 5

I don't want my loved ones to know everything about my health

I am comfortable with those close to me knowing everything about my health

Look at your answers. What role do you want your loved ones to play? Do you think that your loved ones know what you want, or do you think they have no idea?

What do you feel are the three most important things that you want your friends, family, and/or doctors to understand about your wishes and preferences for end-of-life care?

1.

2.

3.

STEP 3: Go

When you're ready to have the conversation, think about the basics. **Mark all that apply:**

Who do you want to talk to?

- | | |
|---|---|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Faith leader (Minister, Priest, Rabbi, Imam, etc.) |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Sister/Brother | <input type="checkbox"/> Other: |

When would be a good time to talk?

- | | |
|--|--|
| <input type="checkbox"/> The next holiday | <input type="checkbox"/> The next time I visit my parents/
adult children |
| <input type="checkbox"/> Before my child goes to college | <input type="checkbox"/> At the next family gathering |
| <input type="checkbox"/> Before my next trip | <input type="checkbox"/> Other: |
| <input type="checkbox"/> Before I get sick again | |
| <input type="checkbox"/> Before the baby arrives | |

Where would you feel comfortable talking?

- | | |
|---|---|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> Sitting in a park |
| <input type="checkbox"/> At a favorite restaurant | <input type="checkbox"/> At my place of worship |
| <input type="checkbox"/> In the car | <input type="checkbox"/> Other: |
| <input type="checkbox"/> On a walk | |

What do you want to be sure to say?

If you wrote down your three most important things at the end of Step 2, you can use those here.

HOW TO START

Here are some ways you could break the ice:

“I need your help with something.”

“Remember how [someone in the family] died—was it a ‘good’ death or a ‘hard’ death? How will yours be different?”

“I was thinking about what happened to ____ and it made me realize...”

“I need to think about the future. Will you help me?”

“Even though I’m okay right now, I’m worried that ____ and I want to be prepared.”

What to talk about:

When you think about the last phase of your life, what’s most important to you?
How would you like this phase to be?

Do you have any particular concerns about your health?
About the last phase of your life?

What affairs do you need to get in order, or talk to your loved ones about?
(Personal finances, property, relationships)

Who do you want (or not want) to be involved in your care?
Who would you like to make decisions on your behalf if you’re not able to?
(This person is your health care proxy.)

Would you prefer to be actively involved in decisions about your care?
Or would you rather have your doctors do what they think is best?

Are there any disagreements or family tensions that you’re concerned about?

Are there important milestones you’d like to be there for, if possible?
(The birth of your grandchild, your 80th birthday.)



Where do you want (or not want) to receive care?
(Home, nursing facility, hospital)

Are there kinds of treatment you would want (or not want)?
(Resuscitation if your heart stops, breathing machine, feeding tube)

When would it be okay to shift from a focus on curative care to a focus on comfort care alone?

This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your doctor or nurse if you'd like them to suggest more questions to talk about.

Remember:

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances change.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don't have to cover everyone or everything

Now, just go for it! Each conversation will empower you and your loved ones. You are getting ready to help each other live and plan for end of life in a way that you choose.

STEP 4: *Keep Going*

Congratulations! Now that you have had the conversation, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

Is there something you need to clarify that you feel was misunderstood or misinterpreted?



Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who tend to disagree)?



How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?



What do you want to make sure to ask or talk about next time?



Health, Legal, Financial and End-of-Life Discussions



A national survey by The Conversation Project found that 9 in 10 Americans want to discuss their loved ones' and their own end-of-life care, but approximately 3 in 10 Americans have actually had these types of conversations. For older adults, families and close friends these conversations may be tough to initiate, but they are valuable and necessary for all involved.

You can learn more about beginning conversations about end-of-life care from **The Conversation Project** (theconversationproject.org). Additionally, you can learn more about what community resources may be available through programs like **The Eldercare Locator** (eldercare.gov).

Why is it Important to Have the Conversation With Loved Ones?

Initiating conversations about health, legal, financial and end-of-life issues may be difficult for you and your loved ones, but having these conversations will ensure that a plan is created that accurately reflects your wishes and prepares and engages those who you love. A conversation can provide a shared understanding of what matters most to you and guide your loved ones if and when they need to make decisions on your behalf. Planning in advance will save time, energy and money, allowing everyone to think about what they want for the future.

Preparing for the Conversation

Prior to talking openly with loved ones, it may be useful to gather your thoughts.

Remember:

- Get yourself ready. Think about the conversation.
- It might be useful to write a letter—to yourself, your family or a friend.
- Consider having a practice conversation with a friend.
- These conversations may reveal that you and your loved ones disagree on some things. That's okay. It's important to simply know this, and to continue talking about it now—not during a crisis situation.



Thinking about basic aspects of the conversation may also be helpful.

Here are some areas to consider:

- Select a time to talk. Holidays, family get-togethers and other special occasions are all times when family and friends gather together, presenting an opportunity to include many of your loved ones in these conversations.
- Determine the location for the conversation to take place. A location you and your loved ones are comfortable with such as your home, on a walk or at a park.
- Decide who should be involved in the conversation.
- Make a list of the topics that are most important for you to discuss.

CONVERSATION REMINDERS:

- **Be patient. Some people may need a little more time to think.**
- **You don't have to steer the conversation; just let it happen.**
- **Don't judge.**
- **Nothing is set in stone. You and your loved ones can always change your minds.**
- **Every attempt at a conversation is valuable.**
- **This is the first of many conversations—you do not have to cover everything right now.**

What to Talk About

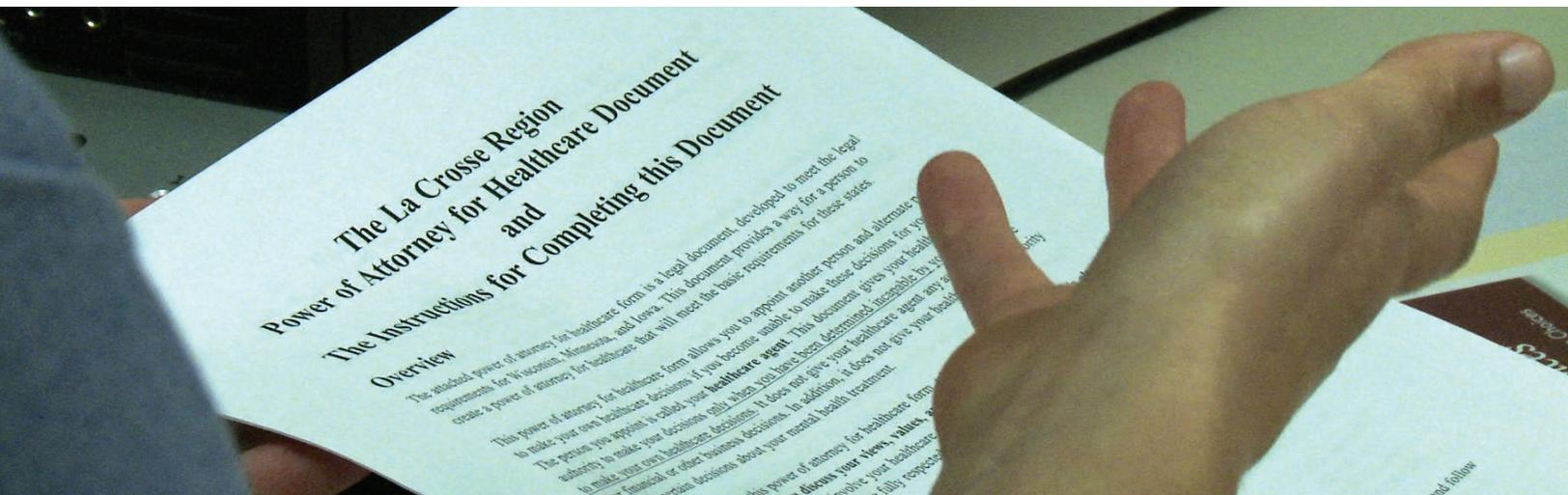
There may be a variety of topics you want to address in these conversations. Here is some guidance on possible health, legal, financial and end-of-life considerations. This list doesn't cover everything you may need to think about or discuss, but it offers a good place to start.

Health

Awareness of any health conditions and the location of useful health information will help avoid any confusion or mistakes later on. **Some of the useful health documents include:**

- List of your doctors and pharmacy contact information
- Medical Records
- Medicare and/or Medicaid Number and Identification Card
- Insurance Policies
- Living Will
- Durable Power of Attorney for health care
- List of medications you are taking, dosage and cost

For more information on this topic and detailed checklists that will help organize health documents, visit **AARP's Prepare to Care: A Planning Guide for Families**. The **Conversation Project's** resource **How to Talk to Your Doctor** (theconversationproject.org) can also be useful when communicating with doctors and nurses.



Legal

There are various legal and medical documents where your advance planning wishes can be recorded to ensure they will be honored when needed. Here are some of the steps to consider in advance care planning:

- Appoint a Durable Power of Attorney for property matters, and fully discuss finances and plans with them.
- Determine if a Trust arrangement is useful.
- Create a Will.
- Choose an agent under a Health Care Power of Attorney and fully discuss health care expectations and wishes with them and other important people.
- Create a Health Care Advance Directive and note if it only includes a Health Care Power of Attorney or a Living Will, or if it is comprehensive and includes both.
- Talk with your physicians about your wishes and provide them with a copy of the Health Care Advance Directive.
- Place legal, personal and financial papers in an easily found location and share that location with the agent and essential loved ones.
- Identify where legal help can be provided for any planning questions.

After completing the legal tools, it is important to make these tools available. For financial planning tools, such as a durable power of attorney, an agent should have access to an original copy and any legal advice should be followed. For a health care advance directive, a copy should be provided to the doctor to place in the medical record. The agent should also have a copy, and should be aware of how to obtain the original document. It is important to continue to review documents and make sure they reflect any changes in circumstances or thinking. For more information on the legal aspects of the conversation, visit abanet.org/aging

Creating legal documents is only part of what is needed. Just as important, is talking with family and loved ones about what the documents mean and how you want decisions made, if you are unable to make decisions for yourself. The conversation about your wishes is just as important, maybe more important, than the actual legal documents.

Legal Terminology

- **Advance Care Planning:** The process of planning for your future care.
- **Health Care Advance Directive:** A general term for a document that provides instructions about your health care. This often includes Living Wills and Durable Powers of Attorney for Health Care.
- **Living Will:** A document where you state your wishes about your medical treatment preferences if you become unable to speak for yourself. It helps to ensure your wishes are known and carried out, though it does not appoint an agent.
- **Health Care Power of Attorney (or Health Care Proxy):** Enables you to appoint another person to make any or all health care decisions for you if you become unable to make your own decisions. You may also include guidelines for those decisions. This helps to ensure your doctor and loved ones are aware of and will respect your wishes. It also helps relieve the stress and conflict caused when family has to guess what you would have wanted.
- **Durable Power of Attorney (for Property):** A document in which you (the “principal”) give legal authority to another person (the “agent”) to act on your behalf when you become too sick or disabled. The appointed agent or agents are whom you want to manage any part or all of your affairs: financial, personal or both. Instructions and guidelines can be included.
- **Trust:** An arrangement where one person or institution called the Trustee holds the title to property for the benefit of other persons called Beneficiaries. This is useful for lifetime management of property where there is a substantial amount of property and professional management is desired. It may also be written to continue after death.

Financial

When having legal, health or end-of-life conversations with loved ones, you should also determine and record where critical financial items will be stored to prevent future confusion. **Documents should include:**

- Birth Certificate
- Social Security Card
- Life Insurance Policy
- Long-Term Care Insurance
- Mortgage or Rental Documents
- Utility Bills
- Car Insurance/Title
- Bank Records
- Credit Cards
- Passwords to Online Accounts
- List of Assets and Debts
- List of Household Bills
- Federal and State Tax Returns
- Bank Contact or Financial Planner
- Contact Information
- Power of Attorney

For more information on maintaining financial information, visit **AARP's *Prepare to Care: A Planning Guide for Families***.

End-of-Life Issues

Here are some considerations when discussing end-of-life care:

- **When you think about the last phase of your life, what's most important to you? How would you like this phase to be handled?**
- **Any particular health concerns.**
- **Who do you want (or not want) to be involved in your care?**
- **Who would you like to make decisions on your behalf if you're not able to? (This person is your health care proxy).**
- **Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?**
- **Who will make decisions on financial and healthcare matters? (They do not have to be the same person).**
- **Are there any disagreements or family tensions that you're concerned about?**
- **Acceptable and/or unacceptable medical treatment/care.**
- **Any important milestones to meet if possible.**
- **Acceptable and/or unacceptable places to receive care (home, nursing facility, hospital).**
- **When would it be okay to shift from a focus on curative care to a focus on comfort care alone?**
- **What affairs should be in order and discussed with loved ones (personal finances, property, relationships)?**

For more information on beginning the conversation on end-of-life care, visit theconversationproject.org.

Keep the Conversation Going

Every conversation you have will empower you and your loved ones to truly understand each other's wishes. After the first conversation, it is important to write down what was discussed and to continue talking with family and friends when necessary. **A way to ensure wishes reflect any changes in thinking following a life change is by reviewing plans when any of the "5 Ds" occur:**

- | | |
|---|---|
| <input type="checkbox"/> Every new Decade of life | <input type="checkbox"/> After any significant Diagnosis |
| <input type="checkbox"/> After the Death of a loved one | <input type="checkbox"/> After any significant Decline in functioning |
| <input type="checkbox"/> After a Divorce | |

QUESTIONS ABOUT YOUR LONG-TERM CARE NEEDS

Do I need to plan for my long-term care needs before they arise? Yes.

This is perhaps the most important question of all! Exploring services when you are already in crisis is a difficult and frustrating process and often your personal preferences are the first to go. Explore your options NOW so that if and when the need arises you will have a plan in place that includes the people, settings and preferences that are most important to you.

Will Medicare and Social Security pay for my long-term care needs? No.

Although Medicare and Social Security are important benefits, they do not provide the type of ongoing supportive services (e.g. meals, bathing, caregivers, transportation, home modifications) that people often must explore when health declines and long-term care needs arise. It is important to understand what Medicare covers and how much your social security benefit will be as you plan for your future needs.

Will most people who need long-term care have to go to a nursing home? No.

The truth is only about 10% of the population live in nursing homes which means the majority of persons who need long-term care stay at home, using home and community based services in combination with their own support networks (e.g. family, friends, neighbors).

KNOW YOUR OPTIONS

What is PCOA Partners in Planning?

Partners in Planning for Long-Term Options is a decision-support process where individuals, family members and/or significant others can find assistance in planning for their long-term care needs.

Partners in Planning Specialists:

- **Help people identify their goals and preferences.**
- **Encourage consideration of all options and possibilities.**
- **Help explore the pros and cons of each of the options.**
- **Encourage orientation towards the future and future needs.**

We can help!

There is a simple fee of **\$75 per person** and **\$125 per couple**.

Thinking about your future?

Partners in Planning provides a comprehensive approach:

- **Education and information through a face-to-face consultation.**
- **Resource materials about the options available.**
- **A personalized plan to guide your decisions.**



**To schedule a Partners in Planning session, call:
PCOA Help Line 520-790-7262**



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