

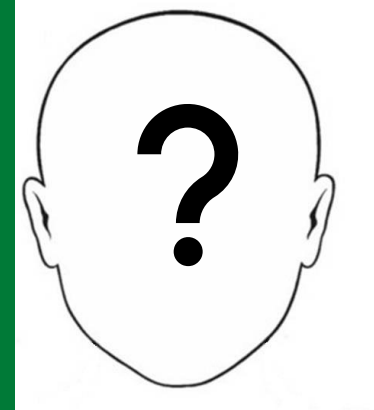


Health Literacy and Advance Care Planning

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Health Literacy Impacts us ALL



We all live healthier when we understand health information



1 of 5 Healthy People 2030 Overarching Goals

Eliminate health disparities, achieve health equity, and attain health literacy to improve the health and well-being of all.

<https://health.gov/healthypeople/about/healthy-people-2030-framework>

Personal health literacy
degree that each of us can

Find
Understand
Use

information and services to inform health
decisions and actions

<https://www.nlm.gov/guides/intro-health-literacy>

This definition emphasizes:

- Use health information rather than just understand it
- Make “well-informed” decisions rather than “appropriate” ones

DHHS/ODPHP, 2020

Organizational health literacy

degree that organizations equitably enable persons to find, understand, and use information and services to inform health decisions and actions for themselves and others.



Impact on



Individuals , families, and communities



Health care delivery systems



Governments, employers, and insurers,

Major stakeholders in health literacy

Fig. 5. Major stakeholders involved in health literacy



World Health Organization (2013)
Health Literacy the Solid Facts. P
10.

<https://apps.who.int/iris/handle/10665/326432>

Patients With Low Health Literacy...



- ❑ Use less preventive services
- ❑ Are more likely to visit an emergency room
- ❑ Have poorer management of chronic diseases like heart failure, lung disease, high blood pressure, diabetes
- ❑ Have longer and more hospital stays
- ❑ Are less likely to follow treatment plans
- ❑ Experience more hospital readmissions
- ❑ Have higher mortality rates
- ❑ Respond less to public health emergencies
- ❑ Encounter more medical errors

Adults with low health literacy have

- 4 times higher health care costs
- 6% more hospital visits
- 2 day-longer hospital stays

Compared to those with proficient health literacy

Source: Partnership for Clear Health Communication at the National Patient Safety Foundation.

Costs financially

Estimated cost of low health literacy to U.S. economy = up to \$236 billion every year.

If account for the future costs of low health literacy (from current actions or lack of action), the real present-day cost of low health literacy is closer in range to \$1.6 trillion to \$3.6 trillion.



FIGURE 3-1 Health literacy and the bottom line.
SOURCE: As presented by Stanton Hudson and R. V. Rikard at Building the Case for Health Literacy: A Workshop on November 15, 2017.

J. Vernon, A. Trujillo, S. Rosenbaum,
and B. DeBuono. Low Health Literacy:
Implications for National Health Policy.
University of Connecticut, 2007.

CURRENT LITERACY LEVELS

- Average American reads at the 8th grade level
- 1 of 5 read below 5th grade level
- Most health information is written at 12th grade level or above



<https://www.healthycle.org/understand-health>

- Nearly 9 of 10 adults struggle with health literacy.
- Those with high literacy skills can have low health literacy

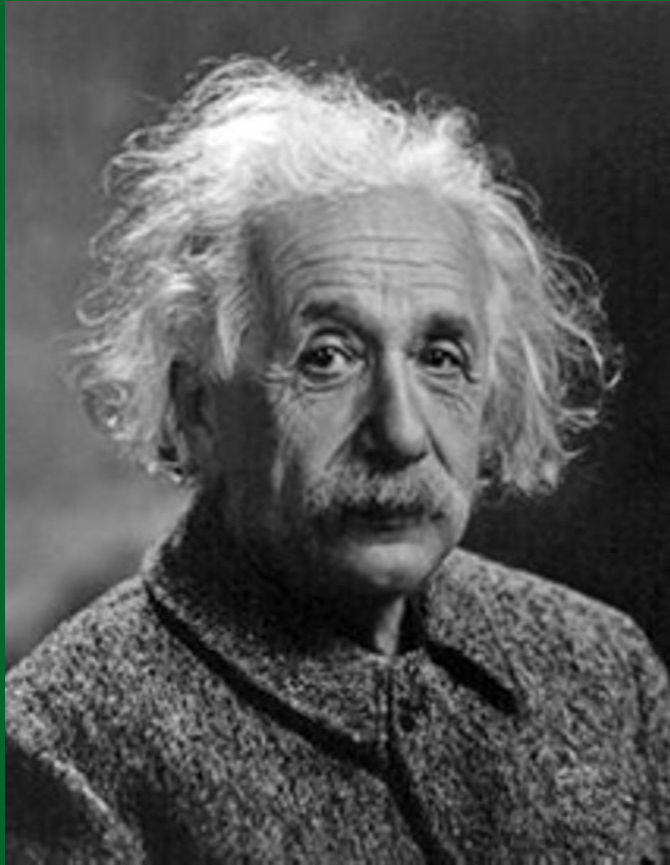
What we know about learning....

Up to 80 % of medical information given by healthcare providers is forgotten immediately by patients.

Almost ½ of information that you remember is incorrect.

If you read well & are okay with numbersthere can still be a problem if you..

- don't know medical terms or details of anatomy.
- have to read statistics and weigh risks and benefits of treatments.
- are diagnosed with a serious illness and are scared/confused.
- have a condition(s) that require multi-step self-care.
- are voting on an issue that impacts your community's health and need to rely on unfamiliar technical information.



Any intelligent fool can make things bigger and more complex... It takes a touch of genius - and a lot of courage to move in the opposite direction.

Albert Einstein

Time for action

<https://hladvocacy.healthliteracymonth.org/>



2023 United States Health Literacy Policy & Press Event

Monday, October 2, 2023 • 11:00 AM – 12:30 PM EDT

OHLP <https://www.ohiohealthliteracy.org/>





Advance Care Planning

Advance care planning is a process that

...supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

The goal is to ensure that we receive medical care that is consistent with our values, goals and preferences during serious and chronic illness.

Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JA, Korfage IJ, Ritchie CS, Kutner JS. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *Journal of pain and symptom management*. 2017 May 1;53(5):821-32. <https://doi.org/10.1016/j.jpainsymman.2016.12.331>

Advance WHAAT?

Advance Care Planning

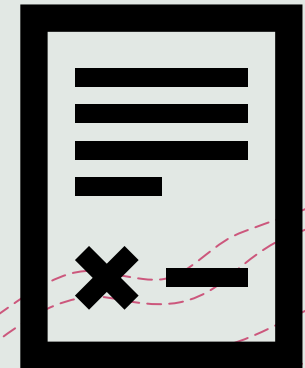
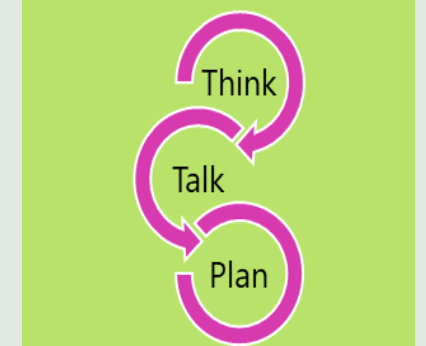
Planning process for “what if”

Advance Directives

Legal documents that give instructions about your health care wishes in case cannot speak for yourself due to a medical condition.

Living Will

Durable power of attorney for healthcare (DPOAHC)



Advance directives

Federal Patient Self-Determination Act 1990, requires all healthcare facilities accepting Medicare to:

- + Provide information about rights to healthcare decision-making.
- + Ask patients if they have an advance directive.
- + Educate staff/community about an advance directive.
- + Not discriminate based on AD status.

How does your agency handle these mandates?

Do you ask these questions?

How do you respond when asked?

Five Myths About Advance Care Planning

Get the facts about these common advance care planning myths.

Myth

I only need a plan if I'm very old or ill.



Fact

It's impossible to predict the future. An emergency can happen at any age. Creating a plan now helps ensure that someone you trust can make decisions that reflect your wishes.

Myth

My loved ones will know what I want when the time comes.



Fact

Not necessarily. In one study, nearly 1 in 3 people guessed wrong when asked to predict which end-of-life decisions their loved one would make.

Myth

I need a lawyer to create an advance care plan.



Fact

Most states offer free advance directive forms online, and you do not have to involve a lawyer.

Myth

An advance care plan only matters if I put it in writing.

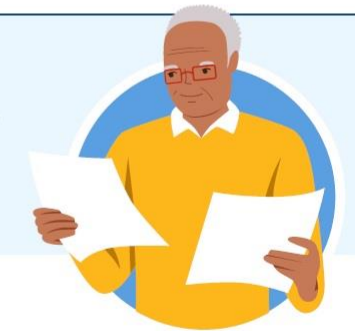


Fact

The most important part of planning is discussing your wishes with your loved ones. It can save them from worrying about whether they made the right decisions for you.

Myth

Once I put my plans in writing, I can't change them.



Fact

Your advance directives can be changed at any time. In fact, you should review your plans at least once a year and after any major life event like a move, divorce, or change in your health.

Advance Care Planning (ACP) linked to

1. Better life experiences
2. Improved communication among healthcare providers, caregivers, and patients
3. Decrease feelings of decision-making burden
4. Better satisfaction with care
5. Medical care that fits with your own wishes

19 Evidence-Based Benefits of Advance Care Planning-
<https://tinyurl.com/19-ACP-reasons>

Evolving personal and practice discussions

Increasing age of Americans (70 million will turn 65 by 2030)

+ Focus on curing disease

+ push to prolong life in chronically and critically ill

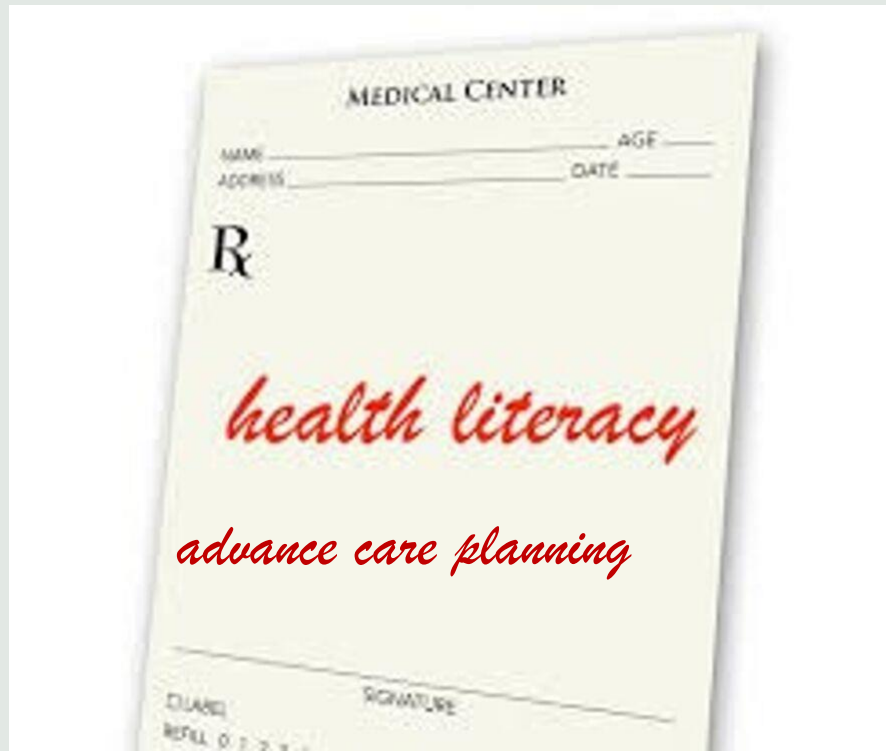
+ ongoing rise in health care costs (example: Medicare cost \$747 billion in 2022)

➡ national discussion about end-of-life decision making and quality of end-of-life care

➡ national discussion about chronic disease and serious illness

Person-centered prescription strategies

Strategies



Mismatched Communication

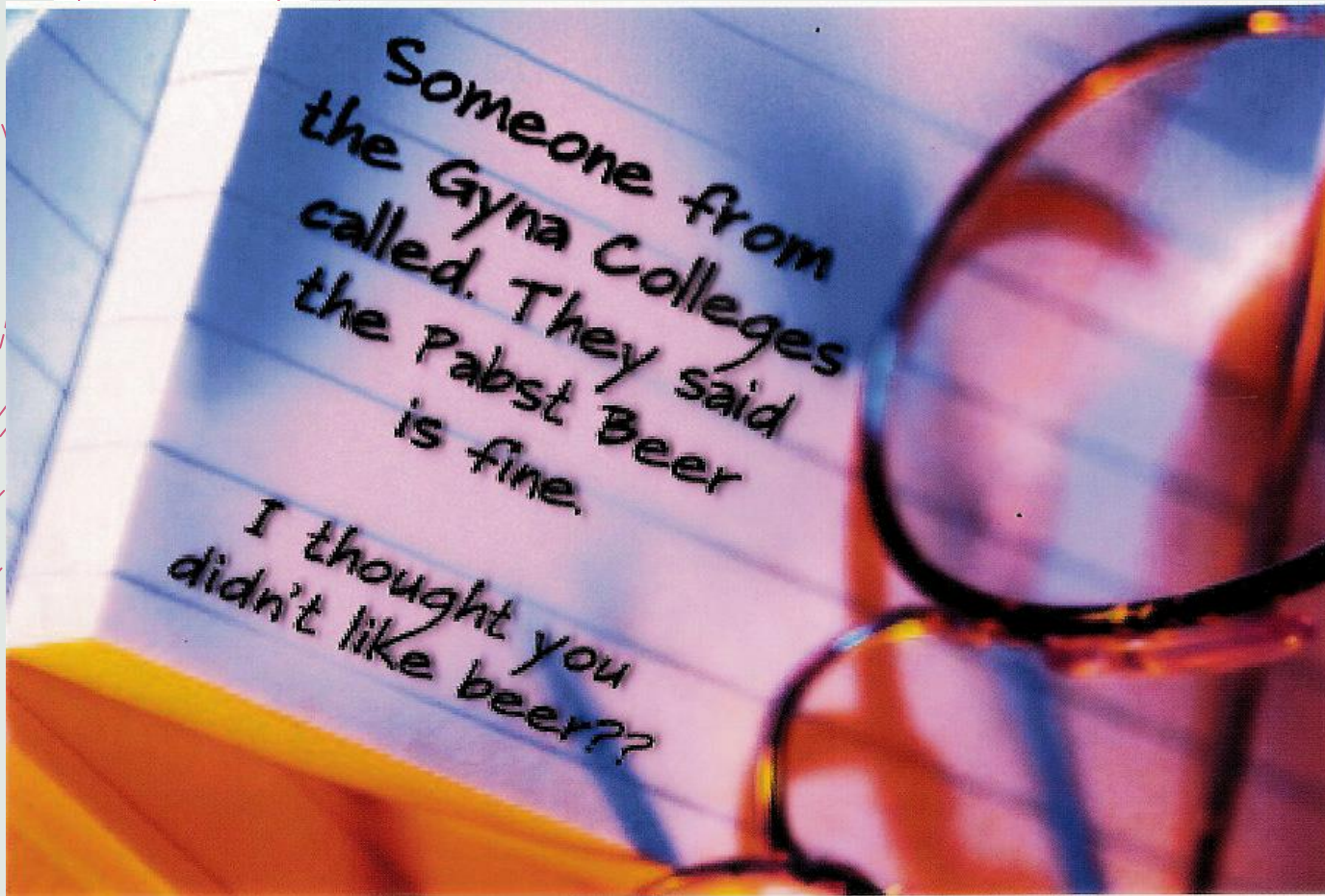
Provider process:

**Giving
information**



Patient process:

**Obtaining,
understanding,
remembering and
acting on
information**



My dad recently got a 3d printer and made a stool sample for his doctor





Universal Precautions

Many are at risk for misunderstanding but not easy to know who

Likewise, we all know life can turn on a dime-but not able to predict

Everyone benefits from clear communication

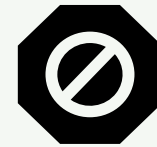
Person -Centered Care

- Show empathy and respect
- Use plain (everyday) language
- Set a shame-free environment
- Encourage interruptions
- Break down ideas
- Avoid jargon
- Avoid abbreviations



<https://www.youtube.com/watch?v=uu7v4yRc4vw>

Grey's anatomy excerpt



Bookshelf

Books

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Treatments for Localized Prostate Cancer: Systematic Review to Update the 2002 U.S. Preventive Services Task Force Recommendation [Internet].

[Show details](#)

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Other titles in these collections

U.S. Preventive Services Task Force Evidence Syntheses, formerly Systematic Evidence Reviews

Health Services/Technology Assessment Texts (HSTAT)

Recent Activity

- Abbreviations - Treatments for Localized Prostate Cancer
- Participant List - Proceedings of the Surgeon General's Workshop on Improving He...
- ohio (6278)
- Proceedings of the Surgeon General's Workshop on Improving Health Literacy
- Nurses Leading Change - The Future of Nursing 2020-2030

See more.

Appendix A Abbreviations

Abbreviation	Meaning
ADT	Androgen deprivation therapy
AHRQ	Agency for Healthcare Research and Quality
AJCC	American Joint Committee on Cancer
AS	Active surveillance
BSFI	Brief Sexual Function Inventory
CAPRA	Cancer of the Prostate Risk Assessment
CaPSURE	Cancer of the Prostate Strategic Urologic Research Endeavor
CARES-SF	Cancer Rehabilitation Evaluation System—Short Form
CI	Confidence interval
DRE	Digital rectal examination
EBRT	External beam radiotherapy
EPIC	Expanded Prostate Cancer Index Composite
FACT-G	Functional Assessment of Cancer Therapy—General
HDR	High-dose radiotherapy (brachytherapy)
HIFU	High-intensity focused ultrasonography
IPCSS	International Prostate Cancer Symptom Scale
KQ	Key question
LDR	Low-dose radiotherapy (brachytherapy)
LHRH	Luteinizing hormone-releasing hormone
MCS	Mental component score
NA	Not applicable
NR	Not reported
PCS	Physical component score
PCSS	Prostate Cancer Symptom Scale
PSA	Prostate-specific antigen
QLQ-C30	Quality of Life Questionnaire for Cancer
QOL	Quality of life
RCT	Randomized, control trial
RD	Risk difference
RP	Radical prostatectomy
RR	Relative risk
RT	Radiotherapy
SD	Standard deviation
SE	Standard error
SEER	Surveillance, Epidemiology, and End Results
SF-36	Short-Form 36-Item Health Survey
T	Tumor stage
TNM	Tumor, node, metastasis
UCLA-PCI	University of California, Los Angeles Prostate Cancer Index
USPSTF	U.S. Preventive Services Task Force

Focus on Effective Listening



Strategies

Focus on person(s) in front of you.

Sit at eye level.

Listen to the message, not what you want.

Repeat back what you hear.

Ask clarifying question(s)

Don't make assumptions.

Don't give an answer until you've heard the message.

Focus on Effective Questioning

- **Get buy-in** by asking for permission
Ask easy yes's (Is it okay if WE talk about...?)”
- **Ask open-ended questions**
“How does the medicine make you feel?” instead of
“Do you have any side effects?”
- **Encourage patients to ask questions (normalize it)**
What questions to you have for me?
Use normalizing lead ins. “A lot of my patients ask about...”
- **Thank for asking questions, bringing lists**
- **Tell me about**

Focus on Key Messages

Need to know

Need to do

Review each point and repeat

Chunk and Check (small bites)



Key Messages: The most important concepts
1st visit for someone about advance care directives

- I don't see on your chart that you have a durable power of attorney for healthcare**
- I see you don't have a person who you have said can make medical decisions for you if you are hurt or sick and can't answer questions**
- Choosing a decision maker is important**
- If you get sick or hurt and cannot make your own decisions, can you tell me who you would want to work with your doctors to make medical decision for you**

Healthy



Chronic disease



End-of-life



Will this drug
help me?*

*= in the moment

If something
happens who will
speak for me?
(AD)

Will this
hospital stay
help me get
back home?*

If I get bad
what is
important?

Will this test/
procedure/ med
help my quality
of life?*

If I get "bad"
what do I do?

Focus on Visits

advance care planning

Strategies

Prepare for doctor visit:

- Ask someone to come with you
- Bring a list of your past and current illnesses and surgeries
- Bring all your medicines
- Carry Ask Me 3 with you
- Bring a list of questions
- Have a plan to record notes

During your doctor visit:

- Ask questions
- Repeat what you think the doctor is telling you
- Take notes (and write new ?)
- Find out if you need to make a follow-up visit
- Ask how and when to reach the doctor if you have more questions

Every time you talk with a health care provider **ASK THESE 3 QUESTIONS**



What is my main problem?



What do I need to do?



Why is it important for me to do this?

When to ask questions

You can ask questions when:

- You see a doctor, nurse, pharmacist, or other health care provider.
- You prepare for a medical test or procedure.
- You get your medication.

What if I ask and still don't understand?

- Let your health care provider know if you still don't understand what you need.
- You might say, "This is new to me. Will you please explain that to me one more time?"
- Don't feel rushed or embarrassed if you don't understand something. Ask your health care provider again.

Who needs to ask 3?

Everyone wants help with health information. You are not alone if you find information about your health or care confusing at times. Asking questions helps you understand how to stay well or to get better.



To learn more, visit ihi.org/AskMe3



Ask Me 3 is a registered trademark licensed to the Institute for Healthcare Improvement. IHI makes Ask Me 3 materials available for distribution. Use of Ask Me 3 materials does not mean that the distributing organization is affiliated with or endorsed by IHI.

Write your health care provider's answers to the 3 questions here:

1. What is my main problem?

2. What do I need to do?

3. Why is it important for me to do this?

Asking these questions can help you:

- Take care of your health
- Prepare for medical tests
- Take your medications the right way

You don't need to feel rushed or embarrassed if you don't understand something. You can ask your health care provider again.

When you Ask 3, you are prepared. You know what to do for your health.



Your providers want to answer 3

Are you nervous to ask your provider questions? Don't be. You may be surprised to learn that your medical team wants you to let them know that you need help or more information.

Like all of us, health care providers have busy schedules. Yet they want you to know:

- All you can about your health or condition.
- Why their instructions are important for your health.
- Steps to take to keep you healthy and any conditions under control.

Bring your medications with you the next time you visit a health care provider. Or, write the names of the medications you take on the lines below.

Like many people, you may see more than one health care provider. It is important that they all know about all of the medications you are taking so that you can stay healthy.

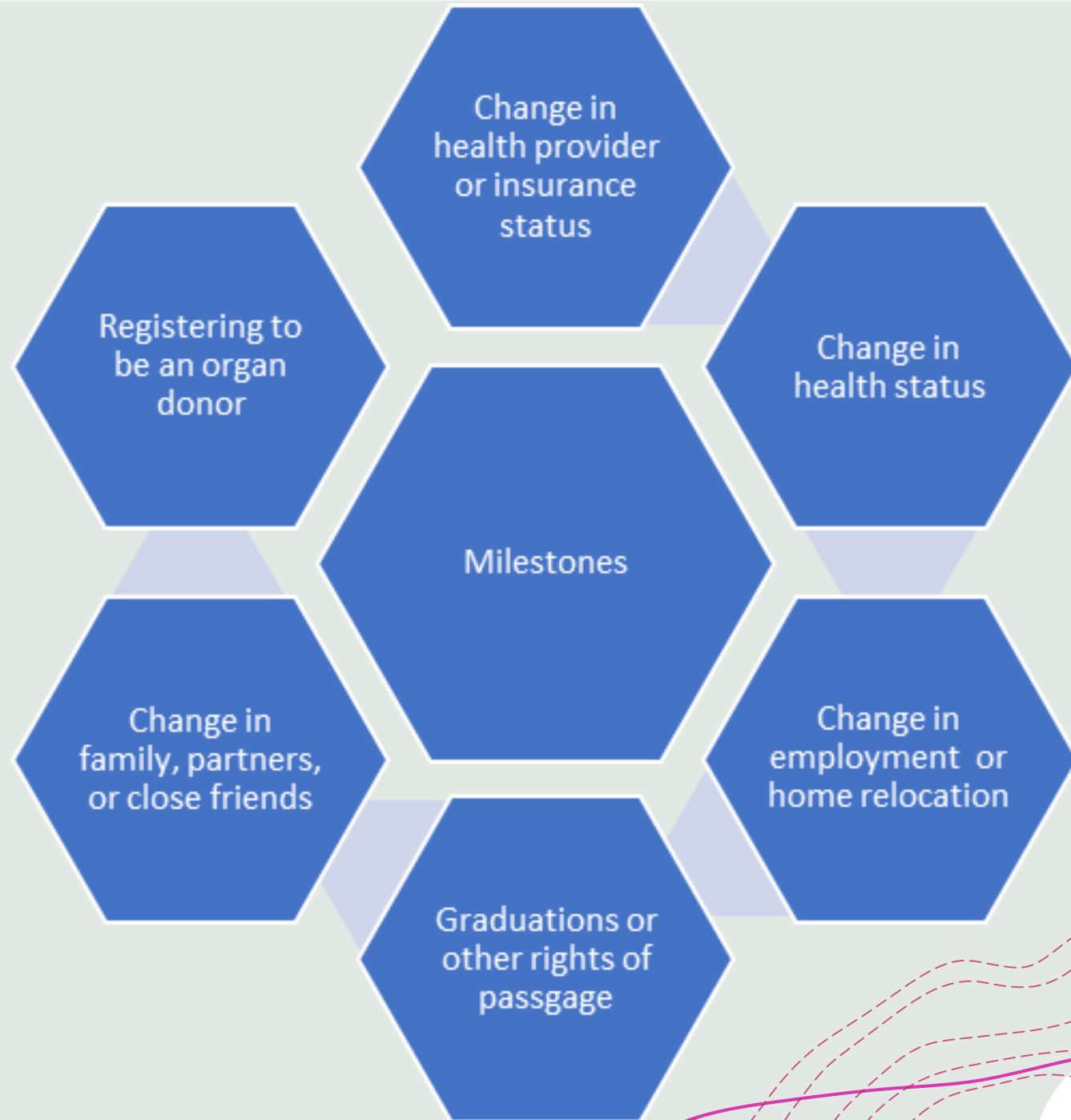
Ask Me 3® is an educational program provided by the Institute for Healthcare Improvement / National Patient Safety Foundation to encourage open communication between patients and health care providers.



Focus on Visits

Ludwick, R., Bakerjian, D., Zalon, M. L., Melander, S. D., & Crist, J. D. (2022). Advance care planning at life milestones. *Nursing outlook*, 70(3), 451–457.

<https://doi.org/10.1016/j.outlook.2022.02.011>



Include Family/Support Person

When interacting with patient:

- Introduce yourself to everyone
- Ask patient what they would like to be called
- Clarify who is room
- Explain you are there to go over plan of care
- Have a seat for extra people
- Ask if others have questions
- Be inclusive of distance communication and note taking and recording

Use Teach back

Ask person to state in their own words what they need to know or do about their health

NOT A TEST

Use chunk and check (not just at end of visit)

Give handouts or write down or draw important steps

????????????????

s: 2 tablet po bid for 3 days, then 1 tablet po bid for 2 days, then 1 tablet po daily for 7 days, then 1/2 tablet po daily for 3 days, then stop.

Strategies

Health Literacy Friendly Educational Materials

Stress what the patient/family need to do

Limit anatomy and physiology

Limit use of contractions

Try to use short words (less than 3 syllables)

Review all educational materials

Health Literacy Resources from Health.gov

<https://health.gov/our-work/national-health-initiatives/health-literacy/resources>


Example Advance Care Planning

[Dr. Rebecca Sudore, MD](#)

<https://prepareforyourcare.org/en/advance-directive>

PREPARE has 2 programs with video stories to help you:

1. Have a voice in **YOUR OWN** medical care
2. Help **OTHER PEOPLE** with their medical planning and decisions



Have a Voice In Your Medical Care

This step-by-step program makes it easy with video examples

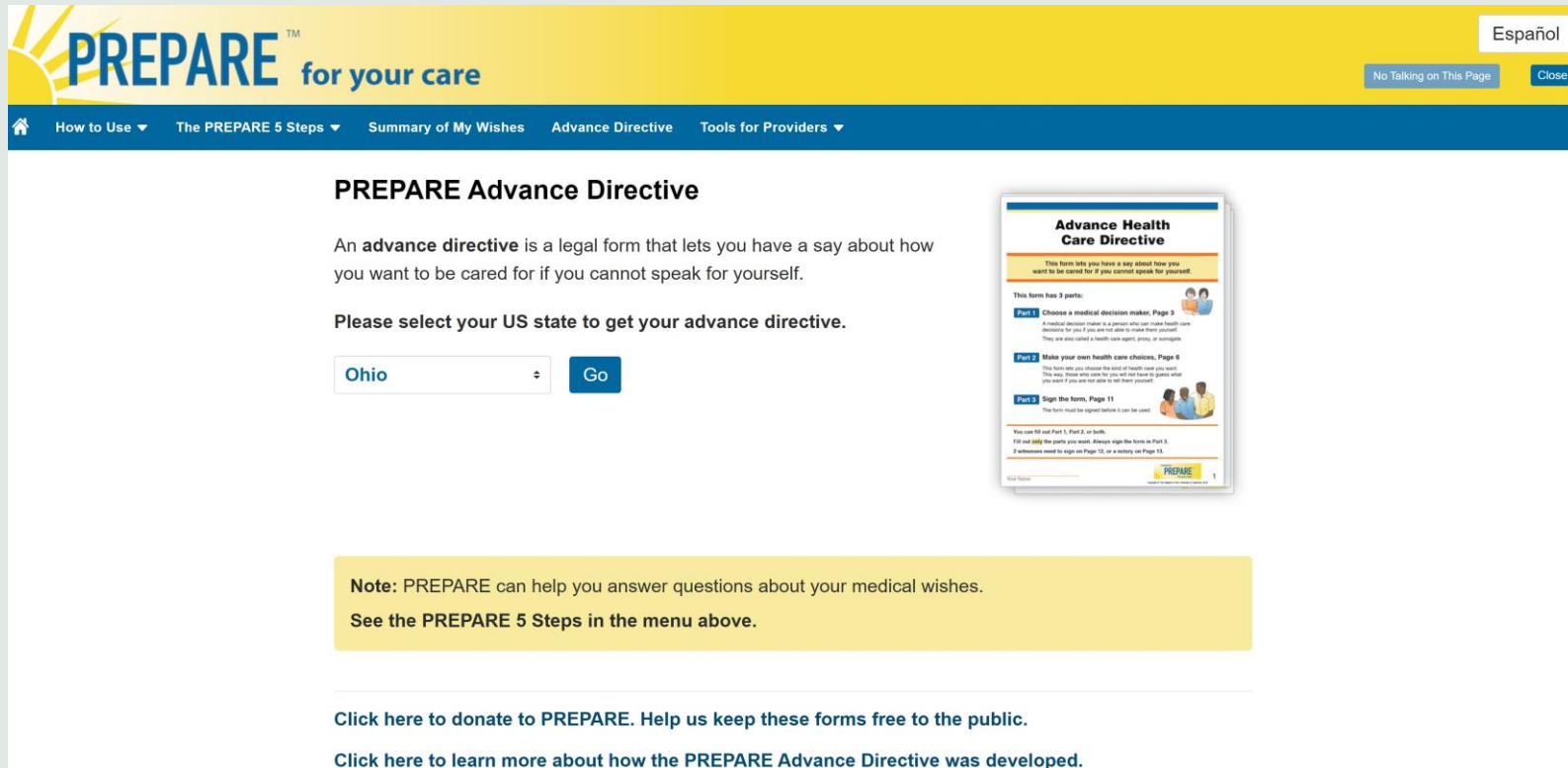
Click here to do [YOUR OWN](#) medical planning



Help Other People

Click here to learn how to help [OTHER PEOPLE](#) with their medical planning and decisions

New!



PREPARE™ for your care

How to Use | The PREPARE 5 Steps | Summary of My Wishes | Advance Directive | Tools for Providers

PREPARE Advance Directive

An **advance directive** is a legal form that lets you have a say about how you want to be cared for if you cannot speak for yourself.

Please select your US state to get your advance directive.

Ohio

Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

- Part 1: Choose a medical decision maker, Page 3**
A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself. They are also called a health care agent, proxy, or surrogate.
- Part 2: Make your own health care choices, Page 6**
This form lets you choose the kind of health care you want. This may depend on how the care will be given and what you want if you are not able to tell your provider.
- Part 3: Sign the form, Page 11**
This form needs the signed names of you and the agent.

You can fill out Part 1, Part 2, or both. Fill out BOTH the parts you want. Always sign the form in Part 3. 2 witnesses need to sign on Page 12, or a notary on Page 13.

Your Name: _____

Note: PREPARE can help you answer questions about your medical wishes. See the PREPARE 5 Steps in the menu above.

[Click here to donate to PREPARE. Help us keep these forms free to the public.](#)

[Click here to learn more about how the PREPARE Advance Directive was developed.](#)



Be an Organization that Advances Health Literacy

Stroke

What has Just Happened to You

What is a stroke or brain attack?

When blood flow to the brain is cut off or significantly reduced, brain cells become damaged or die. The most common type of stroke, called an ischemic stroke, occurs when the flow of blood becomes blocked by a clot, or the vessels become too narrow for blood to pass through. A hemorrhagic stroke is the other type and these are caused by a blood vessel that bursts and releases blood into the brain tissue. The damage to brain cells that results from either kind of stroke, can cause a variety of physical, mental, or emotional disabilities. Since brain cells are constantly sending and receiving messages, cells that are damaged or have died cannot transmit information properly. The more immediately care is given after a stroke occurs, the more likely the patient is to recover some or all of his or her abilities.

How was the stroke diagnosed?

There are several diagnostic tests that doctors can use to confirm whether a stroke had occurred and determine its severity and location in the brain. Imaging tests, such as a CT or CAT (Computed Tomography) scan and MRI (Magnetic Resonance Imaging), are two ways of getting pictures of the brain to locate the problem area. Blood flow tests, which include ultrasound technology or the use of special injectable dyes and X-rays, can provide information on the condition of arteries and can locate and determine the size of any blockages. The third type of diagnostic test is an electrical activity test called an EEG (electroencephalogram) in which small metal disks called electrodes are put on the patient's scalp in order to record the brain's electrical impulses, or brain waves.

What effects might the stroke have?

The kinds of effects and their severity depend on what area of the brain was affected by the stroke and how much damage was done to the brain cells. The following are some of the challenges you may encounter:

Physical Effects

Weakness or paralysis on one side of the body

Problems with balance or coordination

Trouble swallowing

Mental Effects

What is a Stroke or Brain Attack?

A stroke happens when blood flow to the brain is cut off or reduced. Brain cells die or are damaged. There are two kinds of stroke.

- One kind happens when a blood clot blocks the flow of blood to the brain. Or, in some cases, blood vessels are too narrow for blood to pass through.
- Another kind of stroke happens when a blood vessel in the brain bursts. This lets blood flow into the brain tissue.

The faster a person gets care after a stroke, the better the chances that some or all damage from the stroke can be undone.

What happens to a person who has a stroke?

The problems a person has after a stroke depend on


- the part of the brain that was damaged
- the amount of damage that was done

Some warning signs of a stroke:

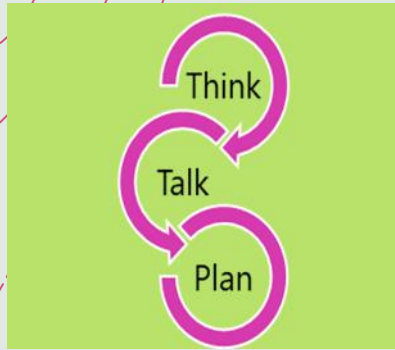
The damage can cause physical, mental and/or emotional problems.

Physical Problems

- weakness on one side of the body

- 
1. Has leadership where health literacy (HL) integral to its mission, structure & operations.
2. Includes HL in planning, evaluation & patient safety, as well as quality improvement
3. Prepares the workforce to be health literate and monitors progress
4. Includes populations served in the design, implementation and evaluation of health information and services
5. Meets the needs of populations with a range of HL skills, but not stigmatizing
6. Uses HL strategies in interpersonal communications and confirms understanding at
7. Provides easy access to health information and services and navigation assistance
8. Designs and distributes print, audio-visual and social media content that is easy to understand and act on
9. Addresses HL in high-risk situations like care transitions & communications about medicines
10. Communicates clearly health plan coverage & costs to individuals

10 attributes



- ✓ Everyone waiting for the “other” to start the conversation
- ✓ Jump start this discussion is easier when know it can decrease confusion, guilt, anxiety and fear for patients and family

“The Conversation Project emphasizes having a conversation on values — what matters to you, not what’s the matter with you.”

Ellen Goodman,
Co-Founder & Director

<https://theconversationproject.org/>



Respecting Choices®
LaCrosse Wisconsin

Summary strategies

Strategies

Lead by example

Normalize discussions

Routinely look for opportunities

Seek out help

Examine your own values



Contact info:

rludwick@kent.edu

<https://www.ohiohealthliteracy.org/>



Additional reference:

<https://www.healthliteracyoutloud.com/>

