End Stage, Palliative & Hospice Care

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Disclaimer

Resources provided by Memorial Health are for the purposes of disseminating information in relation to Care Management. Information is general in nature and people should seek appropriate professional advice about their specific circumstances.

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End Stage

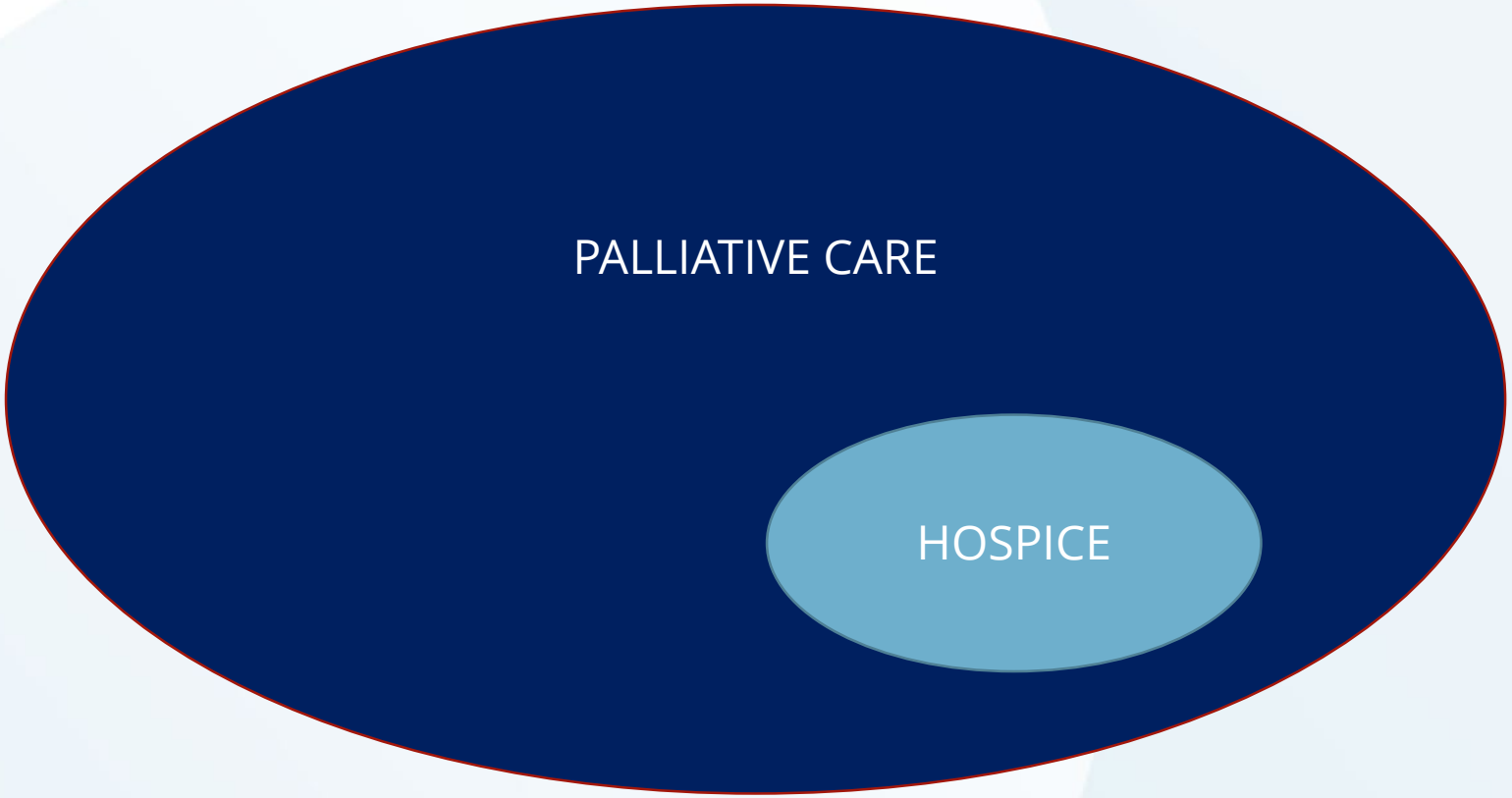
The final stage of the disease, dementia symptoms are *severe*.

Individuals lose the ability to:

- Respond to their environment
- Carry on conversation
- Control movement

Patients are also very vulnerable to infections, especially pneumonia.

PALLIATIVE CARE IS NOT HOSPICE CARE



Objectives

- Define palliative and hospice care and its impact on the care continuum
- Identify who can benefit from palliative and hospice care
- Identify the palliative and hospice care team members and their roles
- Describe the key component of completing Advance Care Planning

Objective 1:

Define palliative and hospice care and its impact on the care continuum

Palliative care is an added layer of support that focuses on providing relief from the symptoms and stress of a *serious illness*. The goal is to improve quality of life for both the patient and the family.

A **serious illness** is a health condition that carries a high risk of mortality and either negatively impacts a person's daily functioning or quality of life or excessively strains his or her caregivers.

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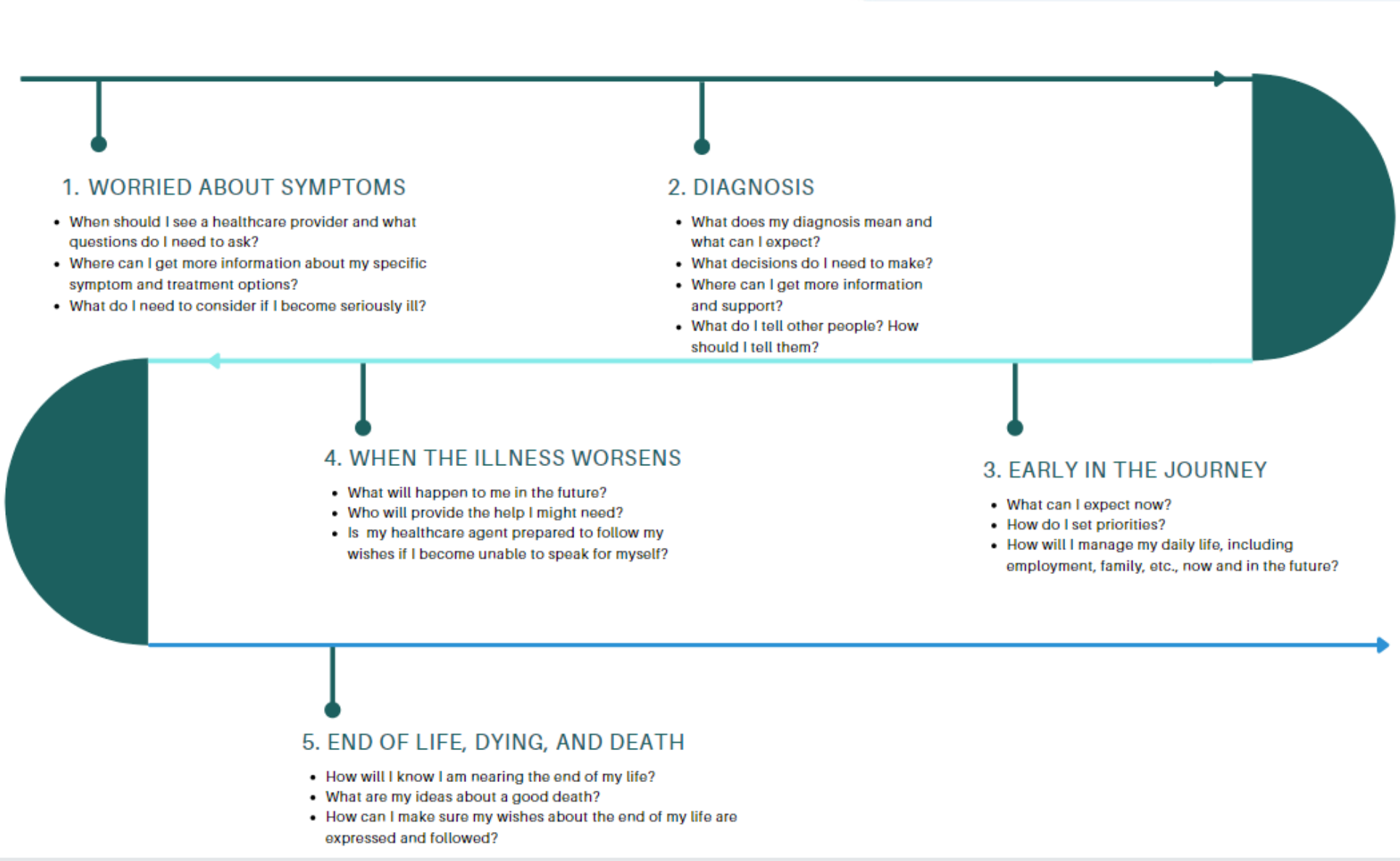
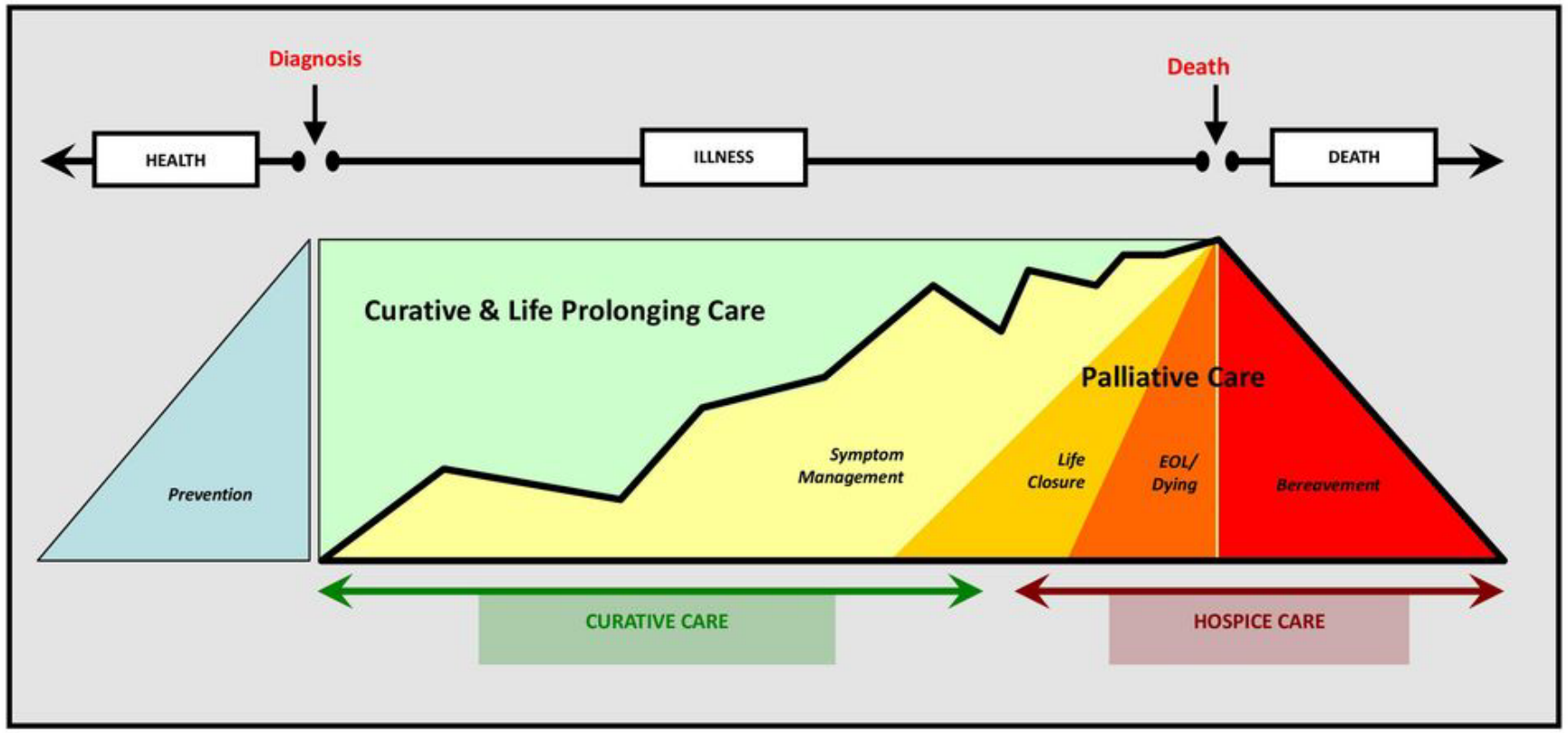
Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers experiencing an advanced, life-limiting illness.

Hospice care provides compassionate care for people in the **last phases** of incurable disease so that they may live as fully and comfortably as possible.

Palliative & Hospice Care Continuum



Palliative Care in the Continuum



Objective 2:

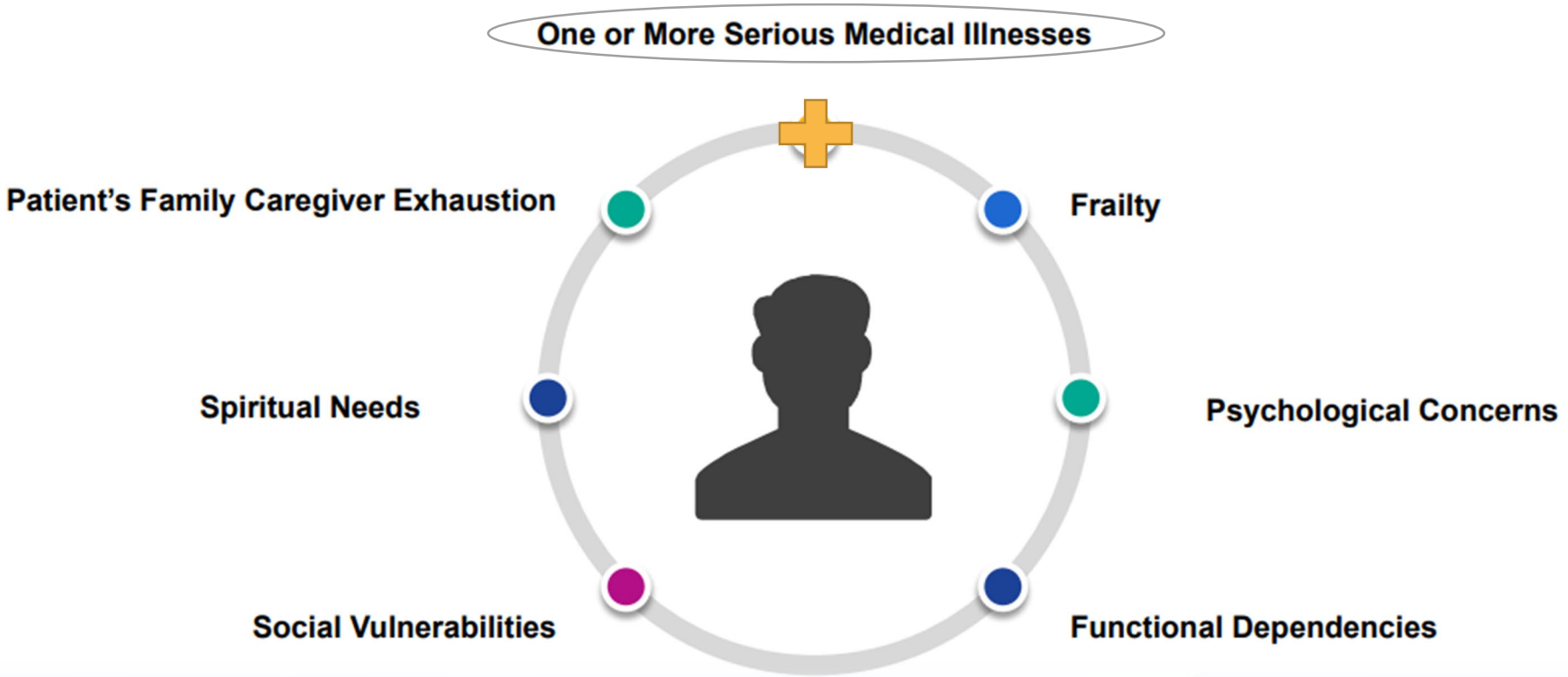
Identify who can benefit from palliative and hospice care

Identifying Palliative Care Needs

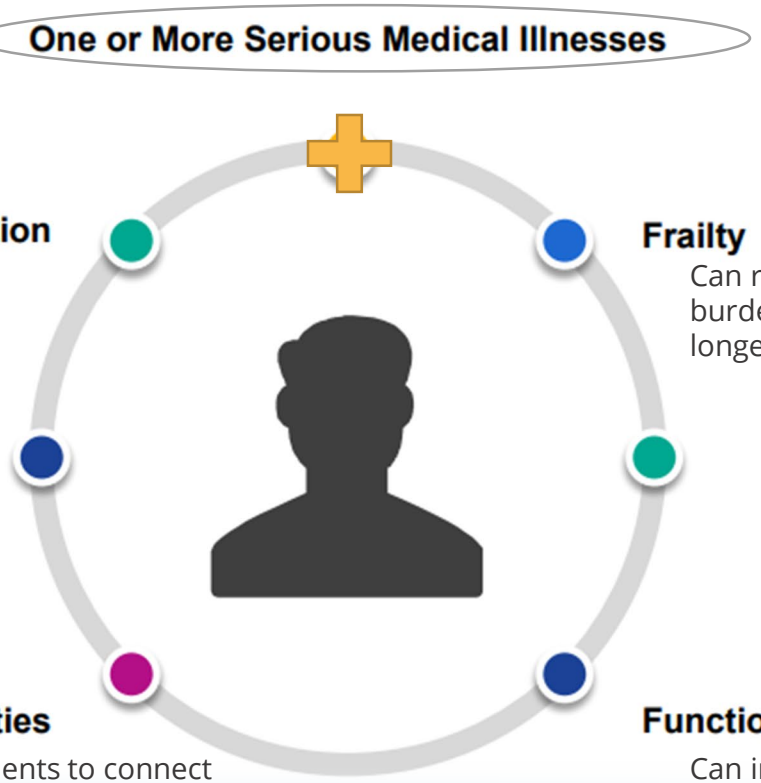
Who is it for?	Those living with a **serious illness**
	Chronically ill patients
Increased Risk for…	Crisis hospitalizations
	Gaps in Care
	Symptoms, pain, & stress

Identifying Patients

Palliative Care may be beneficial for patients with one or more of the following situations/conditions:



Services of Palliative Care:



Patient's Family Caregiver Exhaustion

Can provide support for family and caregivers; help with understanding of treatment plans

Frailty

Can redesign care plan to avoid burdensome interventions that may no longer help

Spiritual Needs

Can provide holistic support that focuses on mind, body and spirit

Psychological Concerns

Can reduce cases of depression and anxiety

Social Vulnerabilities

Can complete assessments to connect patient with needed resources

Functional Dependencies

Can increase independence at home through supportive services

Who benefits from Palliative Care:

Person

Family & loved ones

Care team

Benefits of Palliative Care:

- Improved understanding
- Relief of pain and symptoms
- Family and loved ones support
- Open dialogue

Identifying Hospice Needs

Who is hospice care for:

Benefits of Hospice Care:

Sense of relief and control

Pain & Symptom Management

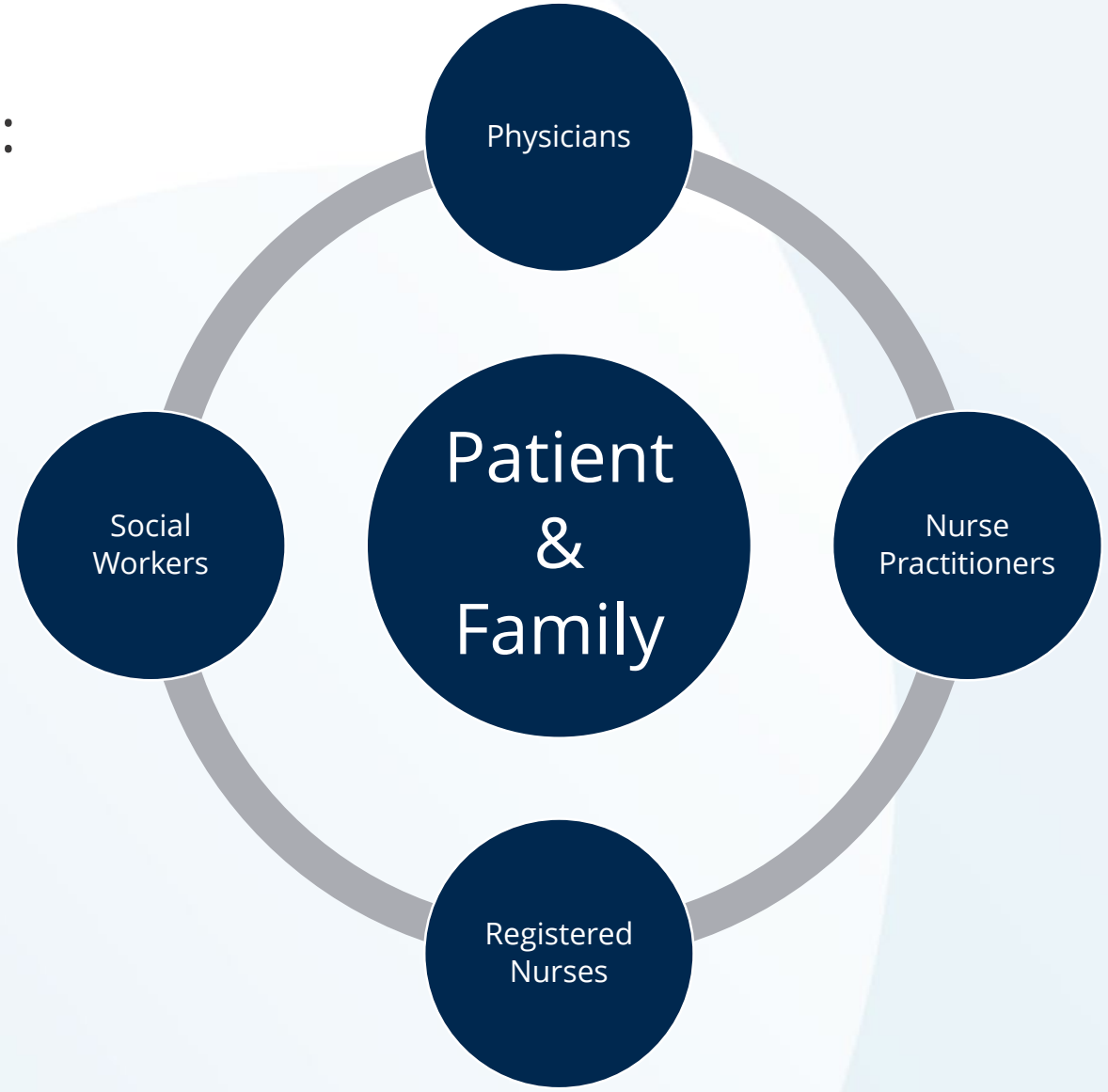
Decreased likelihood of complicated grief

Decreased family/caregiver burden

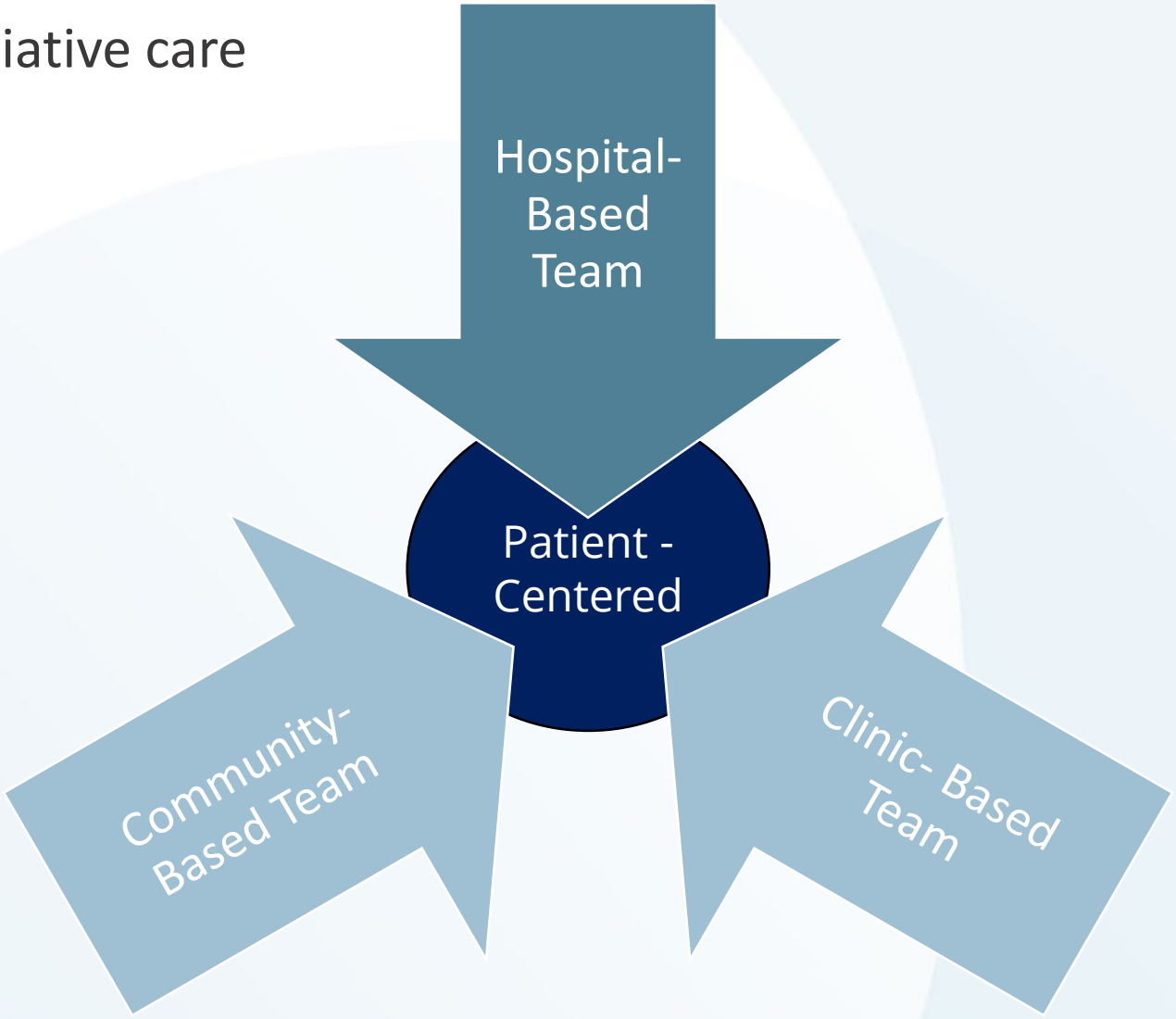
Objective 3:

Identify the palliative and hospice care team members and their roles

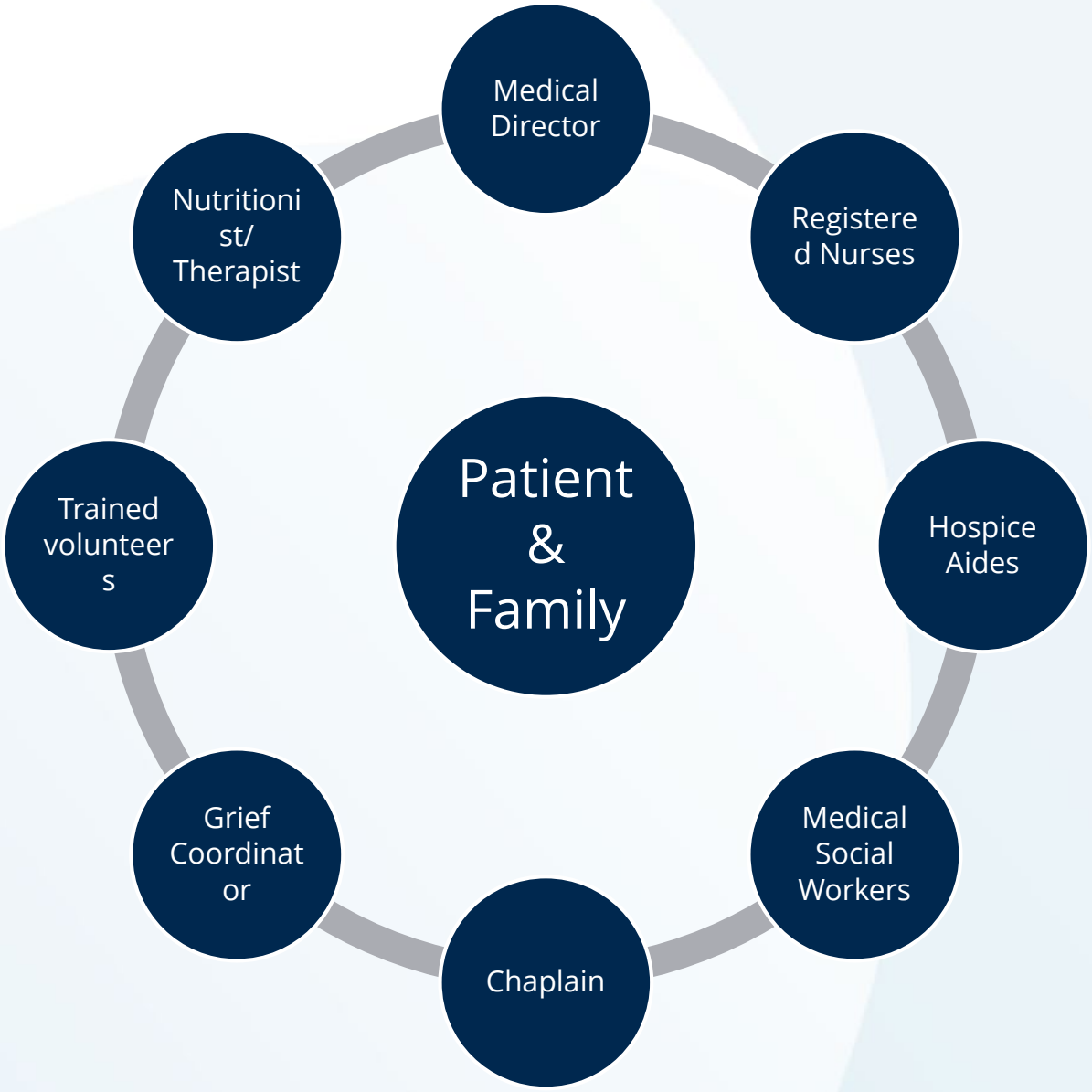
Palliative Care Team:



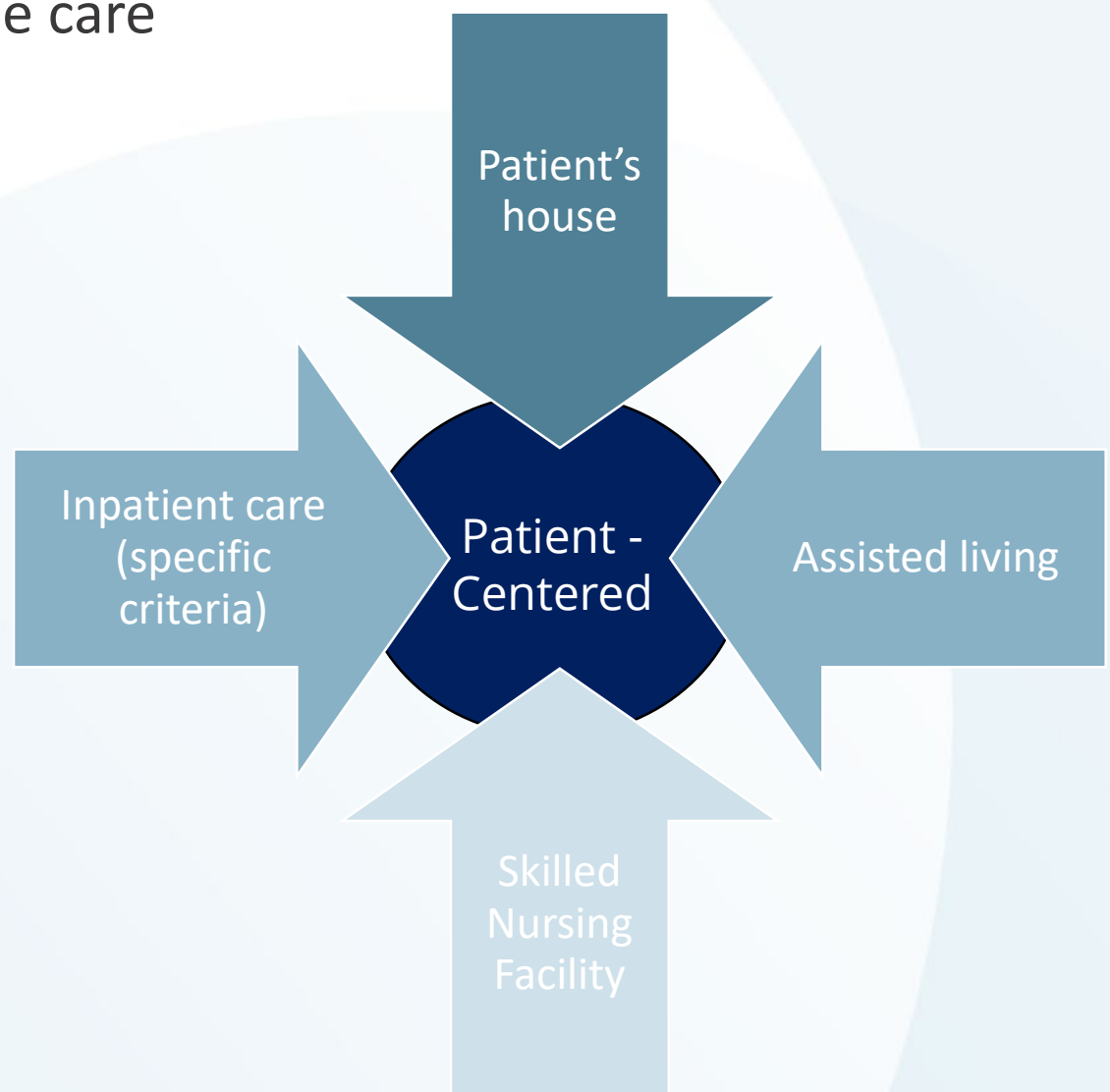
Care settings of palliative care



Hospice Team:



Care settings of hospice care

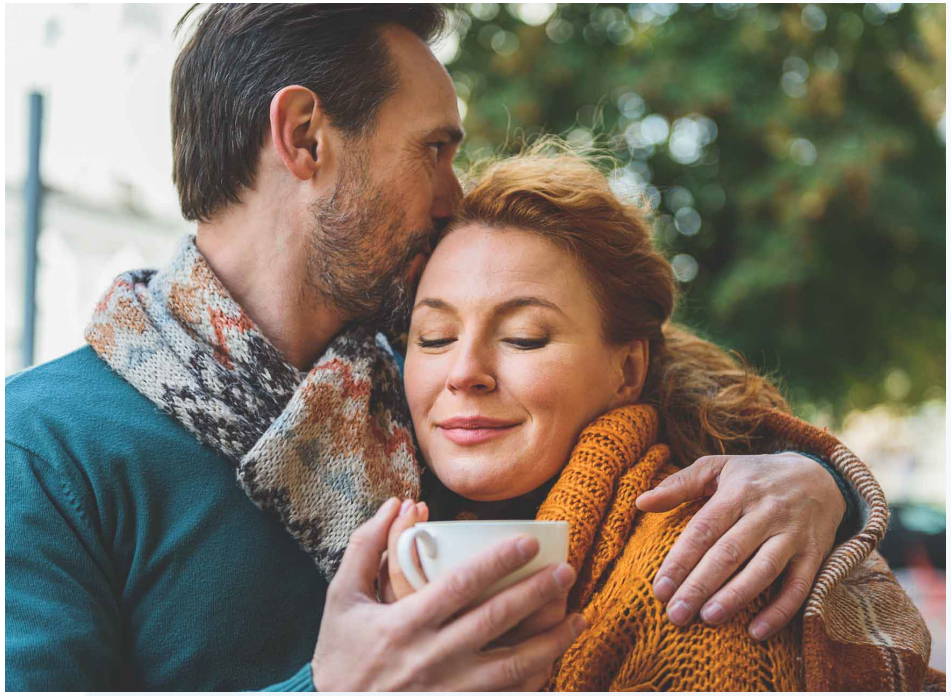


Objective 4:

Describe the key components of completing Advance Care Planning

What can I do now?

Advance Care Planning Considerations



If you were very unwell and not able to communicate your preferences:

- Who would you want to speak for you?
- What would you want them to say?
- Do they know what you want them to say?

What is Advance Care Planning?

Advance Care Planning (ACP) is an ongoing process for all adults regarding their wishes for future healthcare treatment.

Part 1: ACP involves discussion of **medical terms**, addressing **fears or concerns**, identifying **healthcare wishes**, and discussing those wishes with **family and caregivers**.

Part 2: Discussions may include **completion or review of forms** such as an advance directive (power of attorney for health care, living will) or medical orders (POLST form).

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Consent

How are medical decisions made?

For every new procedure or new treatment, your consent (or permission) is required.

You can give or refuse consent yourself, when you are able. If you are too unwell or unable to make decisions, you need an appointed decision maker (agent) to speak on your behalf.

Capacity to make decisions

To make your own treatment decisions, you must be able to:

1) Understand the information about the treatment/procedure
2) Remember the information long enough to make a decision
3) Think about the pros and cons of the treatment/procedure
4) Communicate your decision.

If you can't make these decisions yourself, the doctor will refer to your substitute decision-maker (agent).

Capacity to make decisions

Patients are always assumed to have capacity to make medical decisions unless proven otherwise.

While it may be tempting to speak for your loved one, you should always give them the opportunity to speak for themselves.

Level of decision making required for each decision depends on the nature of the decision

Example: Patient's ability to decide for/against a high risk surgery requires higher level of decision making capacity than the ability required to appoint POA-HC.

The benefits of Advance Care Planning

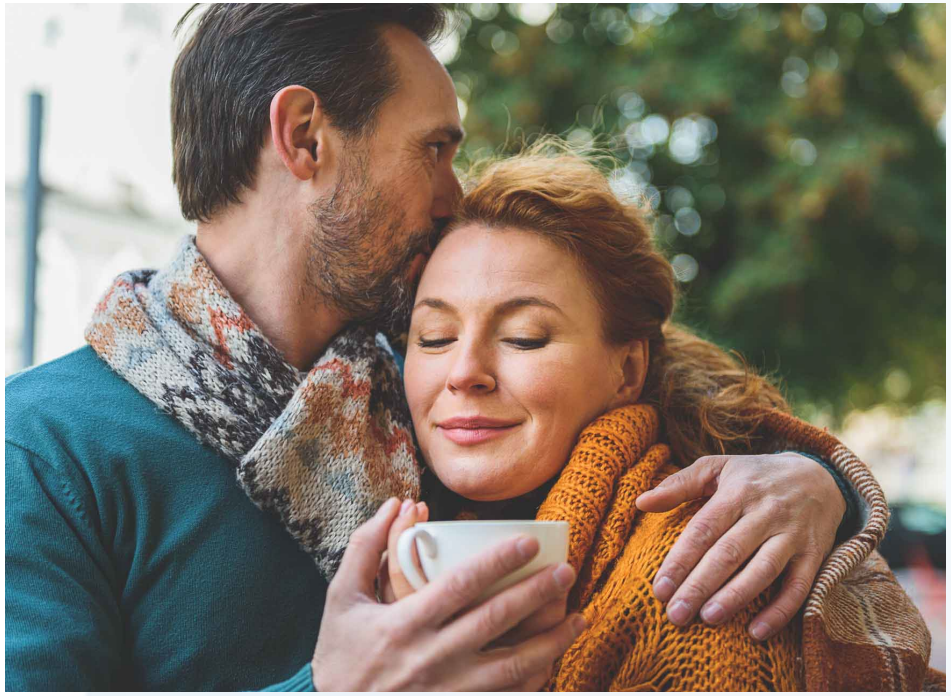
For you (the patient):

- You are able to identify the treatment you would or would not wish to receive
- Peace of mind comes with knowing that others know what you would want

For others:

- Helps to avoid conflict between family/friends if they know what you want
- Minimizes the need to make difficult decisions under stressful situations

Advance Care Planning Considerations



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- Do they know what you want them to say?

Role of a substitute decision-maker (agent)

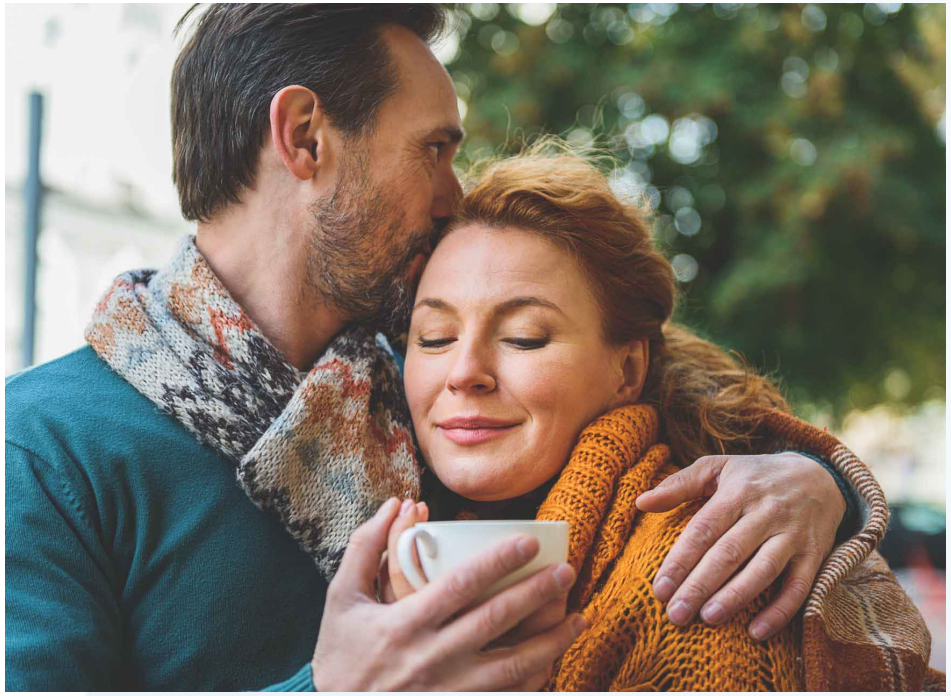
- Makes health care decisions for you if you are unable to make them for yourself
- Can consent to treatment or refuse treatment on your behalf
- Should make their best effort to make the decision that they believe you would make for yourself

How do I choose my substitute decision maker?

The person needs to be:

- ❑ Someone you trust
- ❑ Easily accessible
- ❑ Over the age of 18
- ❑ Able to make complex medical decisions in stressful situations
- ❑ Someone who knows your preferences and what is important to you

Advance Care Planning considerations



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- **What would you want them to say?**
- Do they know what you want them to say?

What matters to you?

- What does a good day look like for you?
- What abilities are so critical to your life that you can’t imagine living without them?
- If you become sick, how much are you willing to go through for the possibility of gaining more time?

Priorities for Medical Care

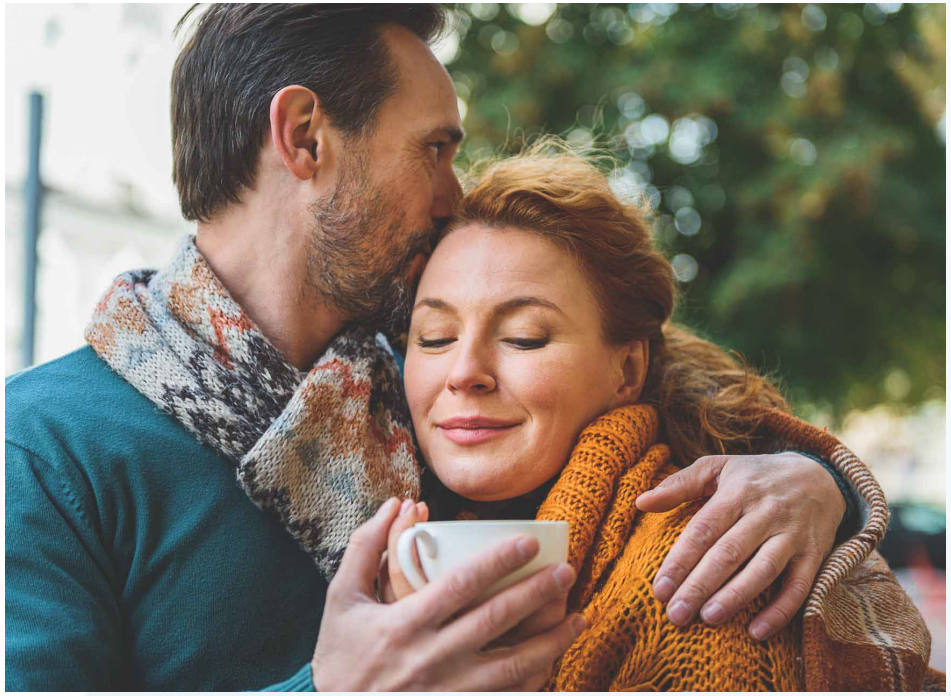
- Living Longer
- Maintaining Current Health
- Comfort

Other considerations

Learn about life-sustaining treatments and other options

- CPR
- DNR
- Medically Administered Nutrition
- Comfort Care

Advance Care Planning Considerations



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- What would you want them to say?
- **Do they know what you want them to say?**

Talk about it!

92% of people say that talking with their loved ones about their healthcare wishes is important.

Only 32% have actually done so.

Be Open

Have a conversation with your:

- Substitute decision-maker
- Treating doctor
- Family, friends, caregivers
- Other advisors

Approaching your support system

How to get started:

- **Crisis situation**

"If _____ happened to me unexpectedly, I would want _____"

- **Family experience**

"I was thinking about what happened to _____ and it made me realize that I ____.

- **Doctor Recommendation**

" My doctor provided me this booklet about care planning and suggested I talk about my general healthcare wishes with you."

Document your wishes

Power of Attorney for Healthcare

A legal document that names a person you wish to make healthcare decisions for you anytime you are not able to speak for yourself

Living Will

A document that provides direction to your loved ones, family members and doctors regarding your preferences for end-of-life care

POLST form

Medical order regarding if cardiopulmonary (CPR) should be attempted if your health and/or breathing stops, typically completed for those living with serious illness

Find forms at memorial.health

Be Heard!

Share copies of your document(s) with:

- Your substitute decision-maker (agent)
- Your family
- Your local hospital(s)
- Your treating doctor(s)

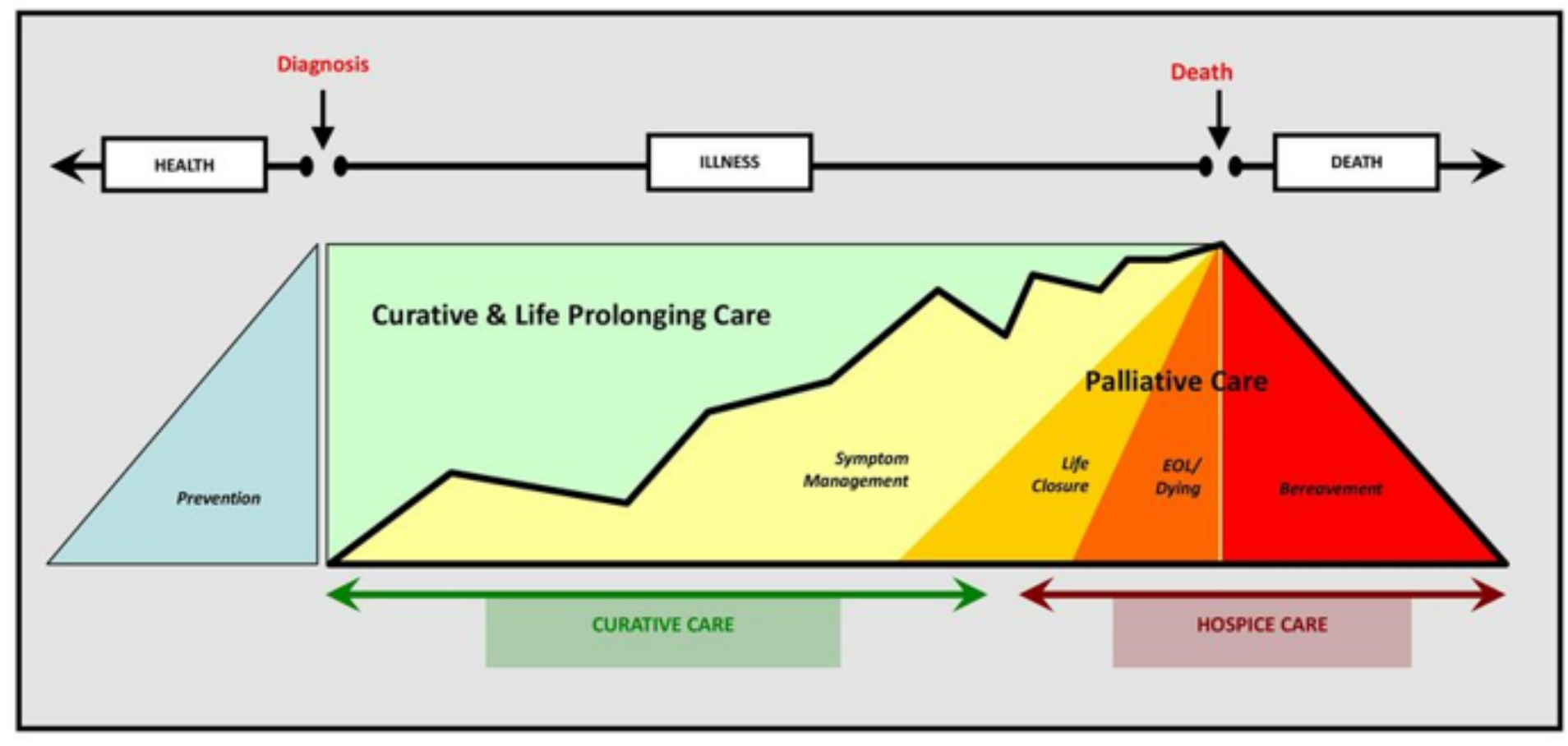
Store the original document(s):

- In an easily accessible area in your home

Do I need a lawyer?

You are able to use a lawyer to make advance care plans, however you do not need to.

Bringing it all together…



Q & A

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