CARE PLANNING

WORKBOOK

ALAMEDA COUNTY CARE ALLIANCE COLLABORATIVE

Advanced Illness Care Program™

GETTING STARTED

At every time of life we want to be treated with respect and have our wishes honored. This is especially true when we are very ill or dying. Yet at this important time, it is likely we cannot speak for ourselves to let others know what we want.

To plan and make your wishes known, there are ***2 things*** you can do. Both are important to make sure your wishes are respected.

1. **Naming a Health Care Agent:**
   This is someone who can speak on your behalf when you are not able to.
2. **Writing Out Advance Directives:**
   This is a document that lays out your wishes for the type of care you want to receive.

The Alameda County Care Alliance Collaborative Advanced Illness Care Program™ (ACCAC AICP) has developed this workbook to help you with these two activities so your wishes are honored. You can talk with your Care Navigator about any part of this workbook. You can also make notes if this is helpful.

Working together with your Care Navigator, you can:

THINK | About your life and your wishes
When you want to think and learn about your choices, turn to page 3.

PLAN | What choices are best for you
When you want to plan and decide about your wishes, turn to page 11.

DO | Record your choices for care
When you want to record your wishes, turn to page 16.

If you would like to talk with either your doctor or your faith leader about advance care planning, please discuss this with your Care Navigator who can help you make these arrangements.

**There is a time for everything,
and a season for everything under the heavens:
a time to be born and a time to die,
a time to plant and a time to uproot,
a time to weep and a time to laugh,
a time to mourn and a time to dance...**

ECCLESIASTES 3

THINKING ABOUT WHAT IS IMPORTANT TO ME

Step 1 will help you learn and think more about the choices you can make. To do this, look over the topics you can share with your Care Navigator and check off anything you would like to discuss.

- ○ I want to hear how others like me have made plans for the care they want (ask your Care Navigator to share the ***"I choose to prepare"*** videos with you).
- ○ I want to think about what makes my life worth living **(turn to *page 4*)**
- ○ I want to think about who might speak for me if I cannot speak for myself (**turn to *page 5***)
- ○ I want to think about what is important to me toward the end of my life (**turn to *page 6***)
- ○ I want to learn more about what treatments I might get when I'm very sick, like a breathing machine. (**turn to *pages 7-9*)**
- ○ I want to think about how I hope to be remembered (**turn to *page 10***)

"The quality, not the longevity, of one's life is what is important.

REV. MARTIN LUTHER KING

I WANT TO THINK ABOUT WHAT MAKES MY LIFE WORTH LIVING

What makes a good day for you? What do you like doing best? What brings you joy?

For example, think about:

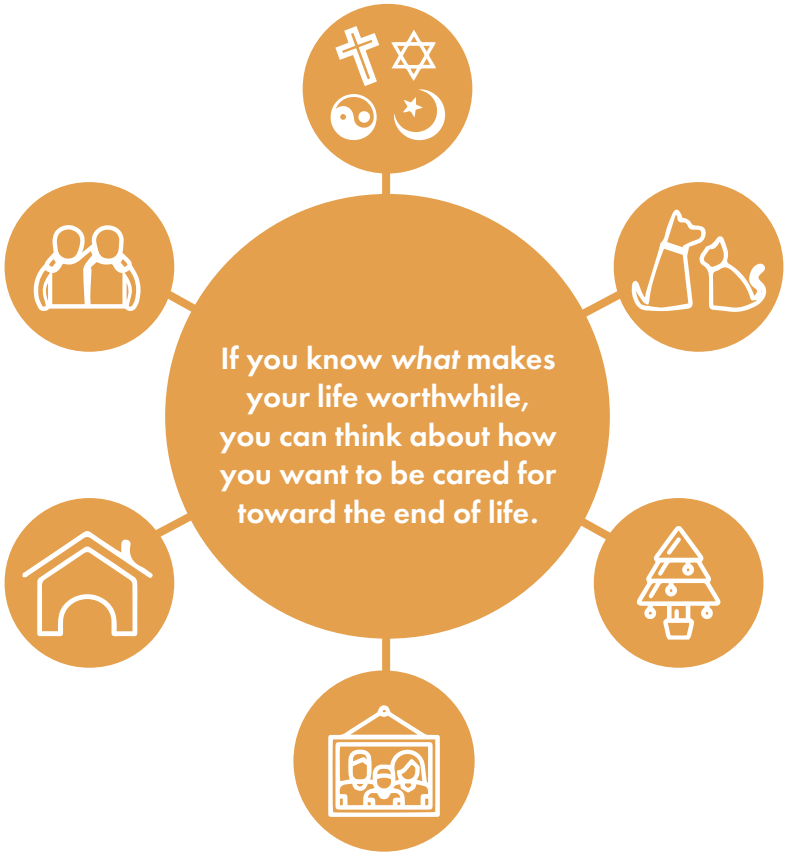
- religion or spirituality
- family and friends
- living in your own home
- having special belongings nearby (like photos or family possessions)
- taking part in family or cultural traditions
- having your pets with you

Are there other special activities or situations that make life worth living for you?

_____

_____

_____



I WANT TO THINK ABOUT WHO MIGHT BE ABLE TO SPEAK FOR ME IF I CANNOT SPEAK FOR MYSELF

If you are seriously ill and cannot speak for yourself, decisions will still need to be made about how you are cared for. You can identify a **health care agent** to speak for you when you cannot make these decisions.

Your health care agent:

- **Must**
  - be at least 18 years old
  - be someone you trust to honor your wishes
  - be able to speak up and ask questions
  - be able to be at your bedside
  - know what your wishes are
- **Can**
  - tell your medical team to start or stop treatments like breathing machines or feeding tubes
  - decide where you will be cared for, whether at home or in the hospital
  - make decisions about how your body will be cared for after death
- **Cannot be your doctor or anyone who works in an institution where you are cared for**

You will need to share what your care wishes are with your health care agent.

If you feel you are ready to decide on your health care agent, turn to ***page 12.***

> **Now we can have a plan. We don't have to wait for the doctor to tell us the plan.**
>
> ACCAC PROGRAM PARTICIPANT

I WANT TO THINK ABOUT WHAT IS IMPORTANT TO ME TOWARD THE END OF MY LIFE

The time may come when medical care can prolong your life, but not improve the quality of your life. This means you may need to choose between a longer life or a higher quality life.

In the difficult situations below, think about whether you would want to live as long as possible or mainly be kept comfortable.

- **Needing others to feed me or bathe me**
  Live as long as possible ***OR*** Mainly kept comfortable
- **Needing others to take me to the toilet or change my diaper**
  Live as long as possible ***OR*** Mainly kept comfortable
- **Not being able to eat and needing a feeding tube**
  Live as long as possible ***OR*** Mainly kept comfortable
- **Not being able to think for myself or understand what is going on around me**
  Live as long as possible ***OR*** Mainly kept comfortable
- **Not being able to speak or communicate with anyone**
  Live as long as possible ***OR*** Mainly kept comfortable
- **Not being able to live unless connected to machines**
  Live as long as possible ***OR*** Mainly kept comfortable
- **Being in a coma, with little chance of ever waking up**
  Live as long as possible ***OR*** Mainly kept comfortable

> **Your voice and what you want really matters.**
>
> **REV. CYNTHIA CARTER PERRILLIAT**
> ***ACCAC EXECUTIVE DIRECTOR***

I WANT TO LEARN MORE ABOUT WHAT LIFE SUPPORT TREATMENTS I MIGHT GET WHEN I'M VERY SICK, LIKE A BREATHING MACHINE

Many medical treatments for critically ill patients provide temporary help while a person heals. When we have an advanced illness we may never heal. Because of this, medical treatments may prolong dying.

IN OTHER WORDS, IT IS IMPORTANT TO REALIZE THAT LEARNING ABOUT MEDICAL TREATMENTS IS NOT ENOUGH.
The important question is whether a treatment, such as a breathing machine, is being used to support healing or to prolong dying.

On the next page (***page 8***) there are brief descriptions of medical treatments you may hear about in the hospital. Your Care Navigator can also direct you to more resources if you want to learn more.

VENTILATOR OR BREATHING MACHINE

"PRESSORS"

DIALYSIS

FEEDING TUBE

TOTAL PARENTERAL NUTRITION

CPR

Ventilator or breathing machine

This machine is connected to the patient through a tube in the nose or mouth. It can also be hooked up through a hole in the neck if a surgery is done to make this opening. Whatever way it is attached to the patient, this machine pushes oxygen into the lungs when they are not working properly or when the patient is too weak to breathe. Often patients on a breathing machine are given medicines to keep them asleep or paralyze them so the ventilator can work better.

"Pressors"

These medicines make the heart pump harder and faster and are used when the heart is not able to work properly. They need to be given through a large IV tube placed near the heart. Because of possible serious side effects, a person who needs "pressors" generally cannot leave the ICU.

Dialysis

This is a treatment used when the kidneys are not working. It cleans the blood of chemicals that would poison the body and lead to death. Dialysis can be done several different ways; many of these ways require being connected to a special machine for several hours, either every other day or even every day.

Feeding tube

This tube generally goes in the nose or directly into the stomach through a surgically created hole in the abdomen. It delivers liquid nutrition when a person cannot eat and swallow safely.

Total Parenteral Nutrition (TPN)

TPN provides all the artificial nutrition needed when a person can't eat. It is used when it is unsafe to use a feeding tube or when the digestive system has stopped working. TPN is given through a large IV tube placed near the heart.

Cardiopulmonary Resuscitation (CPR)

When a person's heart stops, medical teams can press hard on the chest to squeeze the heart and move blood through the body. They also breathe for the person, usually by passing a tube down the throat and connecting it to a bag they can squeeze. In a young, otherwise healthy person whose heart suddenly stops, CPR is often useful and the person can recover completely. In hospitalized patients, recovery after CPR is very unlikely. In people who are seriously ill, there are usually many things that are wrong and resuscitation does not fix them. A recent study found that CPR was always successful in restarting the hearts of ICU patients who needed CPR. But most of these patients died within a day and all of them died before discharge home.

YOUR RIGHTS/YOUR CHOICES

It is important for you (and your health care agent) to know that you have the right to *START*, *REFUSE*, or *STOP* any treatment, including those mentioned here. For example, some people decide they want to die a natural death at home. They can ask to stop artificial feeding or even antibiotics. You can also say that a treatment should be tried for just a while to see if you improve.

Whatever you decide about these treatments, your medical team has the responsibility to assure you are not in pain and that any physical discomforts, such as shortness of breath, are treated.

Write down any treatments (such as use of a ventilator or breathing machine) you would ***NEVER WANT.***

Write down any treatments (such as dialysis) you would ***ONLY WANT TO USE FOR A WHILE*** to see if your body was healing.

I WANT TO THINK ABOUT HOW I HOPE TO BE REMEMBERED

Most of us want to live on in the memories of our friends and families. We want the story of our life to be told to those who come after us. Here you have a chance to think about what you might do to be remembered.

Do you want to think about:

- Special gifts you might leave for others?
- Important messages you want to share?
- Plans for your belongings?
- How to take care of your pet?
- Preparing a will so your resources will be passed on?
- Plans for your funeral, such as speakers, special music or readings you treasure?

We want the story of our life to be told to those who come after us. HOW DO YOU WANT TO BE REMEMBERED?

PLANNING TO GET THE CARE YOU WANT

Step 2 will help you plan to get the care you want and avoid care you don't want. To do this, look over the topics you can share with your Care Navigator and choose anything you would like to discuss.

- I want to decide who will be my health care agent (**turn to *page 12***)
- I want to invite someone to be my health care agent (**turn to *page 13***)
- I want to talk over my care choices with my family and friends (**turn to *page 14***)
- I want to discuss how I want to be remembered (**turn to *page 15***)

If you would like to talk with your doctor, your faith leader or your attorney about advance care planning, please discuss this with your Care Navigator who can help you make these arrangements.

THIS STEP HELPS YOU GET THE CARE YOU WANT AND AVOID THE CARE YOU DON'T WANT.

I WANT TO DECIDE WHO WILL BE MY HEALTH CARE AGENT

As a reminder, your health care agent:

- **Must**
  - be at least 18 years old
  - be someone you trust to honor your wishes
  - be able to speak up and ask questions
  - be able to be at your bedside
  - know what your wishes are
- **Can**
  - tell your medical team to start or stop treatments like breathing machines or feeding tubes
  - decide where you will be cared for, at home or in the hospital
  - make decisions about how your body will be cared for after death
- **Cannot be your doctor or anyone who works in an institution where you are cared for**

WRITE DOWN THE NAME OF AT LEAST 1 PERSON YOU ARE THINKING ABOUT ASKING AND THEIR RELATIONSHIP TO YOU

Name: _____Relationship to you: _____

Name: _____Relationship to you: _____

Name: _____Relationship to you: _____

Who seems to be best qualified?

Who is most likely to be quickly available at your bedside?

Who is the easiest to talk with about your wishes?

Who do you trust the most?

BASED ON ALL THIS THINKING, WHO WILL YOU ASK TO BE YOUR HEALTH CARE AGENT?

Name: _____

I WANT TO INVITE SOMEONE TO BE MY HEALTH CARE AGENT

Talking about advance care planning can be hard. This is especially true if it is the first time you are discussing how you want to be cared for when you are very sick.

To begin, you may want to consider starting something like this:

- "I would like to ask for your help. I need someone who would speak for me and make my wishes known if I am very sick and can't speak for myself."

Be sure this person:

- Asks any ***questions*** they have about being your health care agent.
- Knows that they ***can say no.***
- ***Listens to what you want*** for your care and what you don't want.
  To do this, you can look at **step 1** in this workbook and talk over things like what makes your life worth living or medical treatments.
- Understands that they ***must make decisions like they think you would make*** for yourself about treatments and care.
- Knows ***you trust them*** to make these decisions for you.

You trust them to remember, for example, what you said about what made life worthwhile, and whether you would want treatment to continue.

You may want to name an alternate health care agent. This person would only be called on if your health care agent was not able to speak for you. Be sure to discuss having an alternate with both people, so they both are aware of their responsibilities.

In Step 3 you and your health care agent will fill out the forms to let everyone know about this special relationship.

*See **page 17** if you are ready to complete this document.*

I WANT TO DISCUSS MY CARE CHOICES WITH MY FAMILY AND FRIENDS

There are important reasons to discuss your wishes for care with family and friends.

- There will be less conflict and confusion when the time comes. It gives everyone a chance to listen to what you want and ask questions.
- You can be firm about wanting your wishes honored.
- You can let everyone know who your health care agent is.
- We need voices speaking up for the importance of advance care planning. By telling others you are planning ahead, you help them think about this.

Think carefully about how to begin these conversations and choose family members or friends who are likely to listen calmly. This is better than someone getting agitated and dramatic when they hear you speak about your wishes.

Maybe you can talk with:

- A close relative who has health challenges themselves.
- A friend who recently lost a friend or relative and shared with you how awful it seemed in the ICU.
- A friend who is glad hospice got their friend or relative home before they died.

Again, as with your health care agent, it may be especially good to talk over these two parts of this workbook with them.

"What is important to me toward the end of my life" **(on *page 6*)**
"Treatments I might get when I'm very sick" **(on *pages 7-9*)**

Family reunions are a good time to talk and let them know what your wishes are.

REV. JESSE LAND
ACCAC CARE NAVIGATOR

I WANT TO DISCUSS HOW I HOPE TO BE REMEMBERED

In **Step 1** (***page 10***), you had an opportunity to think about ways you want to be remembered. Remember, there is no right way or wrong way to be remembered. Look back over the issues you were pondering in **Step 1** and reach out however feels right to you.

- Some of this may be private and may not be anything you want to discuss except with just a few people.
- On the other hand, you may be the kind of person who likes to share your plans very openly.
- Some information probably needs to be shared. For example, you may have specific requests for a memorial service or funeral to be held in your faith community. If so, you may want to discuss this with your religious leaders to make sure they feel they can do what you want.

EACH OF US IS UNIQUE.
There are no right or wrong answers.
Whatever *your* wishes are,
they need to be
known and honored.

DOING WHAT IS NEEDED TO DOCUMENT YOUR CHOICES

To make your wishes known, there are ***2 things*** you can do. Both are important to make sure your wishes are respected.

1. **Naming a Health Care Agent**
   This is someone who can speak on your behalf when you are not able to.

2. **Writing Out Advance Directives**
   This is a document that lays out your wishes for the type of care you want to receive.

Step 3 will help you officially name a health care agent and/or write out your wishes for care. In this step, you record your choices about care and the name of your health care agent. This is done on specific forms that ***must*** be honored by your doctors and hospitals. If you do not write out your choices about care, your health care agent will do the best they can to make decisions that they think you would want.

Forms that tell others about your wishes must be signed by a notary or by two witnesses. They must be filed with your health care provider to be available whenever you are hospitalized.

Here are the steps to document your choices.

- I want to name my health care agent. (**Go to *page 17)***
- I want to give instructions for my care. (**Go to *page 18***)
- I want to file these forms with my doctor and healthcare system. (**Go to *page 23***)

ALL THE FORMS YOU NEED TO FILL OUT ARE ON THE NEXT FEW PAGES.

Fill out these forms to tell others about your wishes. File them with your health care provider after they are signed by a notary *OR* 2 witnesses. They will be available every time you visit the hospital.

MY HEALTH CARE AGENT

Your Name:_____

I want the person named below to make my medical decisions if I cannot make them myself. I know that this person can ***START***, ***REFUSE*** or ***STOP*** any life support, medical treatment or test. They can decide what happens to my body after I die, such as funeral plans.

PERSON 1

Full name:_____ Relationship:_____

Phone # 1:_____ Phone # 2:_____

Address:_____

City:_____ State:_____ Zip code:_____

If this first person cannot make medical decisions for me, then I want Person 2 to make my medical decisions.

PERSON 2

Full name:_____ Relationship:_____

Phone # 1:_____ Phone # 2:_____

Address:_____

City:_____ State:_____ Zip code: _____

*To make your own wishes about care, go to **pages 18 and 19** and fill out the information there.*

*If you only want to name a health care agent, go to **page 20** to sign this form.*
*Make sure that you have **two witnesses** (**page 21**) or **a notary** also sign (**page 22**)*

MY WISHES FOR CARE

I want my health care agent to make choices for care that respect my wishes. Some people are willing to go through a lot to remain alive. Others value quality of life and would want to focus on comfort and dignity rather than trying to live as long as possible.

1. **In the situations checked below I want to focus on comfort and dignity, not on living longer:**

   - ○ If I were not able to live on my own and needed others to feed me and/or bathe me
   - ○ If I could not eat and needed tube feedings
   - ○ If I were not able to live on my own and needed others to take me to the toilet and/or change my diaper
   - ○ If I were not able to think for myself or understand what is going on around me
   - ○ If I were not able to communicate with anyone
   - ○ If I were not able to live unless connected to machines
   - ○ If I were in a coma, with little chance of ever waking up
   - ○ ***OR I am willing to live through all these things for a chance of living longer***

2. **Is religion or spirituality important to you? (circle one) YES or NO**

   IF YES: What should your health care agent and medical team do to honor your religious beliefs?

   _____

   _____

3. **If you are dying, do you want to be:**
   - ○ At home
   - ○ In the hospital or nursing home
   - ○ Either, I don't care

4. **Is there anything else you want your health care agent and/or family to know so they can honor your wishes? For example, are there people you want with you? Are there arrangements your health care agent and/or family will need to make for your pet?**

   _____

   _____

5. **Check the *ONE CHOICE* below that you most agree with about life support treatment for you at the end of life.** At the end of life some life support treatments can help people live longer but also cause discomfort, side effects, and might mean spending final days in an intensive care unit kept alive by machines and medicines. Many people want these life support treatments because they may allow them to live longer. Others prefer a more natural death even though they may not live as long.

   If you were so sick you would die soon, what would you prefer:

   - ○ **I want to stay on life support treatment even if there is only a small chance that I will ever get better** or live the life I value. Therefore, ***start and continue*** all life support treatments that my medical team thinks might help me live longer.

   - ○ **I do not want to stay on life support treatment if they are not working and there is only a small chance that I will ever get better** or live the life I value. Therefore, try any life support treatments that my medical team thinks might help me get better. But ***stop these treatments if I am not getting better*** and it seems I will never be myself again.

   - ○ **I do not want life support treatments.** I want to focus on being comfortable and prefer a more natural death.

6. **Are there other things you would like your medical team and health care agent to know about you and your wishes?**

THIS FORM CANNOT BE USED UNTIL YOU...

- Sign this form ***AND***
- Have the form signed by 2 witnesses (***page 21***) **OR** a notary (***page 22***)

YOUR INFORMATION

Sign your name: _____ Today's date: _____

Print your first name: _____

Print your last name: _____

Date of birth:_____

Address:_____

City:_____ State:_____ Zip code: _____

Next page for witness/notary signatures

HERE IS WHERE TWO (2) WITNESSES MUST SIGN TO MAKE YOUR DECISIONS LEGAL

When I sign my name below it means that:

- I promise _____ (name of person on previous page) signed this form.
- The person who signed was thinking clearly and no one forced them to sign.
- I know this person who signed or they proved who they were.
- I am at least 18 years old.
- I am not their health care agent or health care provider.
- I do not work for their health care provider.
- I do not work for the place they live.
- One of us is not related to the person who signed **and** will not get any money or property after this person dies.

WITNESS 1

Print your name: _____ Today's date: _____

Sign your name: _____

Your address: _____

WITNESS 2

Print your name: _____ Today's date: _____

Sign your name: _____

Your address: _____

If two witnesses do not sign this form, it must be taken to a Notary Public for certification. You will need to bring a photo ID.

This is done on the next page.

The Notary Public or other officer completing this certificate only verifies the identity of the individual who signed the document to which this certificate is attached. They do not attest to the truthfulness, accuracy, or validity of that document.

STATE OF CALIFORNIA

County of: _____

On_____(date) before me, _____ (name and title of officer)

personally appeared_____ (name of signer)

who proved to me on the basis of satisfactory evidence to be the person whose name is subscribed to within the instrument and acknowledged to me that he/she executed the same in his/her authorized capacities and that by his/her signature on the instrument the person, or the entity on behalf of which the person acted, executed the instrument.

I certify under ***PENALTY OF PERJURY*** under the laws of the state of California that the foregoing paragraph is true and correct.

WITNESS my hand and official seal.

Signature: _____

Place Notary Seal Here:

FILING THESE FORMS WITH YOUR HEALTH CARE PROVIDER AND HEALTH SYSTEM

You have now completed everything that is necessary to make your wishes known if you cannot speak for yourself. Your final job is to make sure that you share this information.

YOU NEED TO:

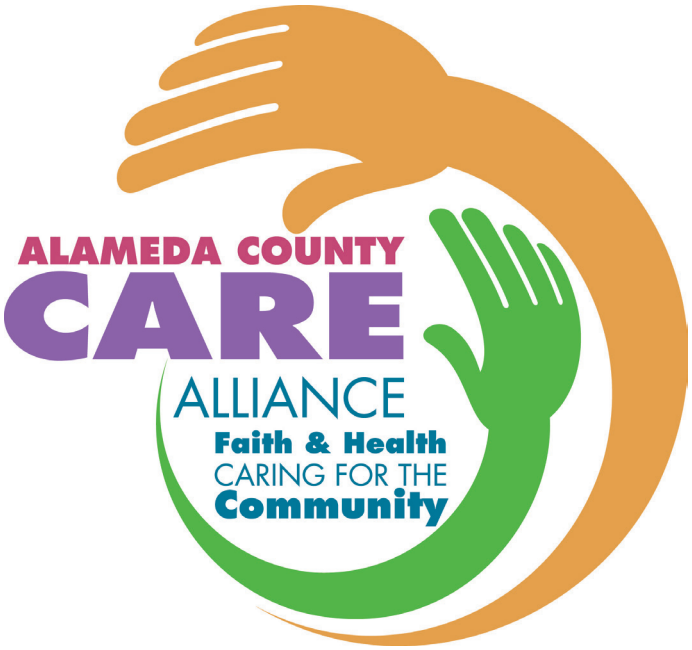
1. **Make copies of completed forms/pages:**
    - "My Health Care Agent" (***page 17***) **and/or** "My Wishes for Care" (***pages 18-19***)
    - Signature (***page 20***)
    - Witness (***page 21***) or Notary (***page 22***)
2. **Give copies to:**
    - **Your health care provider**
      You may want to work with your Care Navigator to prepare for this conversation.
    - **Hospital or Emergency Room**
      Bring a copy with you when you go. Even better, share these pages with your hospital or healthcare system now, because you may be too ill to think about at that time.
    - **Your health care agent and your alternative health care agent if you have one.**
      Be sure you discuss with them what your wishes are and make sure they understand that they are your health care agent.
3. **Share and discuss** these forms with your family and friends.

On a regular basis, you should also review these forms and make sure they continue to accurately reflect your wishes.

In general, it is good to review your care plans when/on the:

1. **Date** of your birth.
2. You have a new **diagnosis.**
3. There is a **death** in the family or among your close friends.
4. You go through a **divorce.**
5. If you notice a significant **decline** in your health.

YOU HAVE EVERYTHING YOU NEED.
Make sure you share your wishes with your friends and family.



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