

# Preparations as You Near the End of Life

Finding out that your cancer can no longer be controlled, or deciding that you don't want any more treatment, can leave you wondering what will come next. You may want to know how much longer you will live, what to expect as your cancer grows, and what you can do to prepare for your death. There are things you can do to prepare yourself and your loved ones for what is to come.

- Planning at the End of Life
- Talking with People as You Near the End of Life
- Coping with Emotions as You Near the End of Life

# Planning at the End of Life

The phrase 'end-of-life' is sometimes used to describe the final days, weeks, or months of a person's life when their cancer can no longer be controlled.

The goal of end-of-life care is to help people prepare for and make decisions about what they want for support and care. This may include palliative care to control symptoms and help the person with cancer and their loved ones cope with coming changes. Hospice may also be an option as the person with cancer gets closer to dying.

- Find out what you can expect near the end of life
- Decide what is important to you

- · Deciding about your end-of-life care
- Palliative care and hospice
- · Getting your personal affairs and finances in order
- Advance directives
- Making decisions for urgent or emergency care
- Organ, tissue and whole body donation
- Meeting personal goals

# Find out what you can expect near the end of life

Finding out that your cancer can no longer be controlled can be scary. But finding out what to expect and what your options are can help.

Ask your cancer care team:

- How long you are likely to live
- What physical and mental changes you are likely to have as your cancer gets worse
- Who can help you manage these changes
- What type of care you will likely need
- What your options are for care now and in the future
- What decisions you will need to make about end-of-life care

## Decide what is important to you

Ask questions, share your wishes, and begin to actively plan the remaining part of your life. It's normal to want to be prepared. Talking about your options and decisions can help everyone involved in your care. Your cancer care team needs to know what you would prefer at the end of your life, such as where you want to receive care. They also need to know about any cultural, religious, or spiritual beliefs or values that might affect your decisions. This will help you and your cancer care team make the best choices for you.

## Deciding about your end-of-life care

Part of end-of-life preparation includes making some decisions about how you would like to be cared for. Things to think about include:

- Where you want to die
- What type of support you want to manage your symptoms
- What type of medical care you want at the end of your life
- Whether you want life-extending treatments or not

No matter your decision, the goal of cancer care at the end of life is to give you the best possible quality of life. It can be helpful to include your loved ones in the decision-making process. Sometimes having a meeting with your cancer care team and your loved ones can help. That way your loved ones can learn about your options along with you. They can also hear what the cancer care team recommends so that they can best understand the choices you make.

Make sure that your loved ones know what your choices are and why you have made your decision. This can be a tough process, and everyone may not agree with your choice. But remember, it is your choice, and you must be comfortable with your end-oflife plan.

Make sure that you have someone who supports your decisions and can stand up for you. Some people might question your decisions. If someone questions you, you can tell them that you have looked at all the options with your cancer care team and made the best choice for yourself.

Keep in mind that decisions do not have to be forever. As your cancer gets worse, you might need to make some different choices. But that's okay – you need to do what's best for you.

# Palliative care and hospice

If your physical or mental health symptoms are affecting your quality of life, things can be done to help you deal with them.

<u>Palliative care</u><sup>1</sup> focuses on helping you and your caregiver manage your symptoms while you are getting treatment. Palliative care can be useful any time you have symptoms that need to be controlled. If you are not ready for hospice, palliative care can be a good option.

<u>Hospice care</u><sup>2</sup> is a special kind of care for people who are expected to live no more than 6 months. It focuses on the quality of person's life so that they can live as alert and pain-free as possible. Hospice care can be given in the home, an assisted living center, a nursing home, or an inpatient hospice program.

# Getting your personal affairs and finances in order

Thinking and talking about dying is hard. But it is to your benefit to put your personal, financial, and legal affairs in order. Planning ahead, and getting help if needed, helps you spend more quality time with your loved ones and can help bring you peace of mind.

You or someone you trust (a family member, friend, or lawyer) can find and organize important legal and financial papers. These may include:

- Your will
- Birth and marriage certificates
- Social Security card/number
- Insurance policies, bank statements, and investment summaries
- Account passwords

If your finances are complex, consider talking with a financial advisor. If you are concerned about leaving your family with high medical bills or debts, a financial navigator or social worker can help. They can work with you to create a plan that reduces stress on you and your family. Your cancer care team can help you find a navigator or social worker. You might also want to let your family know what your wishes are for what happens after you die. Some people take comfort in helping loved ones plan their funeral or memorial service. You can write out instructions, record them on your phone, or talk about them with loved ones.

If you have a pet, think about who you would like to care for them after you die. If a family member or friend cannot take them in, think about posting on a message board in your community, faith group, or other group in your area. You can also contact your local pet shelter or support group to see if they might be able to help you find a new home for your pet.

## **Advance directives**

Advance directives put your decisions about your future health care in writing. Advance directives are legal documents. There are 2 parts to advance directives.

**Living will.** In a living will, you state what medical treatments you do or do not want at the end of your life. For example:

• If your heart stops beating, do you want doctors to try to start it again?

- If you cannot breathe on your own, do you want a breathing machine to do it for you?
- If your kidneys no longer work, do you want dialysis? Dialysis is a mechanical process that filters waste from your blood.
- If you cannot eat or drink, do you want to get food and liquid through a tube?
- If you die, do you want to donate your organs or other body tissues?

**Durable power of attorney for health care.** You choose the person who will make health care decisions for you if you are not able to. This person may also be called a **health care proxy**, **agent**, or **surrogate**. Be sure to choose someone you know will support your wishes.

See <u>Advance Directives</u><sup>3</sup> to learn more about the types of documents, how to create one that meets your needs, and what it means if you have one.

# Making decisions for urgent or emergency care

In an emergency, things can happen very quickly. If the person who you want to make health care decisions for you isn't available, you may get treatments that you don't want. Having a Physician Orders for Life-Sustaining Treatment (POLST) form and, if wanted, a do-not-resuscitate order (DNR) can help.

A POLST form has a set of specific medical orders that you can fill in and ask your health or cancer care provider to sign. A POLST form addresses your wishes in an emergency, such as whether to use CPR (cardiopulmonary resuscitation), whether to go to a hospital and be put on a breathing machine, if necessary, or stay where you are and be made comfortable.

A POLST form has to be signed by a qualified member of your health care team, such as your doctor. Emergency personnel, like paramedics and EMTs (Emergency Medical Technicians) can't use an advance directive, but they can use a POLST form. Without a POLST form, emergency personnel are required to provide every possible treatment to help keep you alive.

In the United States, the POLST form you should use depends on your state. They may be called something else, depending on where you live. You can find a list of the POLST program names on the <u>NationalPOLST website</u><sup>4</sup>.

A **do-not-resuscitate (DNR) order** only applies if your heartbeat and breathing stop and you cannot be woken up. The DNR order tells health care professionals that you do not want them to try and restart your heart and breathing, called **resuscitation**, **cardiopulmonary resuscitation**, or **CPR**.

If you are thinking about a getting a DNR order, talk with a member of your cancer care team. CPR rarely works for people with advanced cancer and, if it does work, there may be lasting brain damage. If a person's goal is to live comfortably for as long as possible and then die gently, they may choose a DNR order to avoid CPR. Like a POLST, a DNR is a medical order and it must be completed by a member of the health care team.

#### Can I change my mind about my advance directive, POLST, or DNR?

Yes. You can change your mind about your wishes at any time and make changes to your advance directive, POLST, or DNR. Check what your state requires to make a change for each of these forms. Those choices are always your decision.

# Organ, tissue and whole body donation

Some people would like to donate their organs or their whole body after their death. But <u>organ donation</u><sup>5</sup> may not be an option for some people with cancer. Any organ donor is checked for medical conditions, including cancer. Whether someone's organs can be used will depend on many things, such as:

- The type of cancer
- If the cancer has spread (metastasized)
- Other medical conditions or infections
- Age

Even if someone is not allowed to donate organs, they may still be able to donate other tissues such as skin or corneas. Or they might be able to donate their whole body for medical education or research. If you would like to donate part or all of your body after your death, ask your cancer care team about options.

Organ and tissue donation instructions can be included in your advance directive. Be sure that your family and those close to you know your wishes about this.

## Meeting personal goals

As you get closer to the end of your life, you might have some personal goals. Achieving them might help your life feel meaningful and complete to you. For example, you might want to:

- Travel somewhere you have dreamed of going
- · Connect with old friends or relatives
- Read a favorite book again or see a favorite movie
- Spend time with people who are important to you
- Attend a special event

# **Hyperlinks**

- 1. www.cancer.org/cancer/managing-cancer/palliative-care.html
- 2. www.cancer.org/cancer/end-of-life-care/hospice-care.html
- 3. <u>www.cancer.org/cancer/managing-cancer/making-treatment-decisions/advance-directives.html</u>
- 4. polst.org/program-names/
- 5. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/can-i-donate-my-organs.html</u>

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# Talking with People as You Near the End of Life

It is important to share your feelings and desires as you near the end of your life. You might want to take some time to think and talk about your life and how you feel about it. People who care about you will want to know how you are feeling and if there's anything they can do for you. And they may need a chance to start getting ready for the loss they will face when you die.

- Your partner
- Your family
- Your friends
- Religious or spiritual counselor

It might be helpful to have your family meet with your cancer care team to help them prepare for your last days. They might want to learn about the dying process, what your wishes are as you approach death, and what they can do to help cope with their grief.

# Your partner

Cancer and the end-of-life can be difficult for both the person with cancer and their partner. Remember that your partner is dealing with their own emotions and probably feels a lot of pressure to be strong and to meet your needs.

The loss of a partner is one of the most stressful events a person can experience. Sometimes partners try to protect each other from the pain they're both going through. If at all possible, talk with your partner about what each of you is feeling. You may find that you're both going through the same kinds of emotions. Try to accept what each person says without judgment, argument, or defensiveness. Simply let each person say what they feel.

This is another chance to try to make any past wrongs right and comfort each other. But having cancer doesn't mean that you won't get angry and frustrated with each other. Try to focus on the comfort you can give each other and let the little things go. Focus on the good times, happy memories, and the times you have been there for each other.

- Try to spend time enjoying each other's company. Watch movies or TV. If you're able to, go for walks. Or just enjoy each other's company.
- Talk about the good and not so good times. What are you most proud of in your life together? What struggles did you go through together? What are your happiest memories of your time together?
- Take time to share your fears and ask your partner what they fear. Try to be open and supportive, even when the topics make you uncomfortable.
- Make sure that your partner understands and will support your wishes for your endof-life care. If they don't feel they can carry out your wishes, let them know that's okay. Find a friend or family member who can do this for you. Some partners have a difficult time with death and wishes around end of life.

#### Alone time

It can help to give each other some personal space and private time. Reassure the other person that you still love them, but it's OK if you both need some time to be alone. This is a common need for anyone facing the end of their life or the loss of a loved one. Make the most of each day, and know each day is a new chance to enjoy each other.

#### Sex and intimacy

At this stage of your cancer, it may be hard to be as sexually close as you have been in the past. You may be tired, in some pain, or simply not interested in sex.

But you can still have physical contact and intimacy in your relationship. Talk with your partner about your needs and if you feel you can have sex. Each person is different and may have different needs. But it's OK if you want to just touch, hug, or hold hands.

Talk with your health care team if you have questions or concerns about sex and intimacy. Ask them what you might be able to do to maintain sex and intimacy.

#### Help take care of your partner

Talk to your partner if you're worried about being a burden because they're taking care of you. Ask how they are feeling. Your partner might show signs of emotional and physical stress, such as depression, headaches, and trouble sleeping.

Encourage your partner to take care of themselves. Ask a friend or another family member to help out if you think there's too much for one person to do. If you decide to ask others to help, be sure to tell your partner. That way you can help take care of your partner, too.

# Your family

Each member of your family is working through their feelings about losing you. There are things you can do to help them. Talk with your family and friends about times you have spent together. You will be honoring your life together and making new memories for them to cherish.

You might also want to resolve conflicts, say goodbye to special people, and tell family members how much you love them. If you cannot or prefer not to talk in person, consider writing, calling, video chatting, or sending a message through a family member.

Remember that some people may not respond the way you hope they will. They might not feel comfortable visiting, or they may be afraid of saying the wrong thing. Or they might not be able to let go of old issues. You can feel comfort that you did your best to heal a relationship or connect with them.Stories can be a gift to the people you leave behind. You might want to write down or record your memories. Or you can ask someone else to write or record as you talk. Sharing your wishes and dreams for loved ones may help ease your concerns about leaving them. It can also help them connect with you at important times in their lives.

#### Adults

You can help adult family members by being open about your cancer, any news you've been given from your doctor, and any other needs you may have. Explore their thoughts and feelings with them. Tell your family that:

- You're willing to talk about anything.
- There may be times you don't feel like talking and you'll let them know when that is.
- You'd rather not have to pretend you're happy if you're feeling tired or down. Explain that this doesn't mean you're not OK.
- You'll be as honest with them as you can be and hope they will do the same

Share with your family what you have learned from your cancer care team about how long you're expected to live, what changes are likely, and what type of care you might need. This will help them prepare and support you as you get closer to death. It also helps to share the expected signs of the dying process, and how to manage them should they occur.

Also tell you family what decision and plans you've made or need to make. Get their input if you want, but know the final decision is yours.

If you have adult children with their own families, they might be juggling their own children, jobs, and caring for you. It can be very stressful. Open, honest communication will help you support each other through this time.

#### Children and teens

Many people try to protect children from bad news, including death. But children of all ages need help preparing for the loss of a loved one. Children can usually sense changes or stress in the household and know when something is wrong. What they imagine is often far worse than anything you tell them.

You might also want to create some sort of memento to be given to certain children at some point after you die. You could write a letter, make a recording, create a slide show, make a scrapbook or a memory box of things you want them to know. These mementos can help the children remember you and know how much you loved them.

For more on talking with children and teens, see <u>Telling a Child Someone They Love</u> <u>Has Cancer</u><sup>1</sup>.

# Your friends

Knowing that someone close to them is dying can be hard for some people. While some friends can be warm, supportive, and want to spend time with you, others might feel awkward around you. They might not know what to say or how to behave.

Talking with your friends might help. Explain that you're the same person and you'd like to spend some time with them. But some people will still be uncomfortable and you might suggest other ways they can stay in touch or support you. It might be easier for them to send you cards, small gifts, or quick social media messages.

# **Religious or spiritual counselor**

Spiritual questions are common as a person tries to make sense of both the illness and their life. This may be true not only for the person with cancer, but for loved ones, too.

Here are some suggestions for people who might find spiritual support helpful.

- Be sure your cancer care team is aware of any beliefs that might affect your care decisions.
- A spiritual counselor might be able to help you find comforting answers to hard questions.
- Religious rituals, such as forgiveness or confession, may be reassuring and bring a sense of peace for some people.
- A search for the meaning of suffering can lead to spiritual answers that can be comforting.
- Strength through spiritual support and a community of people who are there to help can also be helpful to the patient and family members.

For those who are interested, a minister, priest, rabbi, other clergy member, or a trained pastoral counselor can help you identify your spiritual needs and find spiritual support.

# **Hyperlinks**

1. <u>www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-</u> <u>cancer/dealing-with-treatment/talking-to-kids.html</u>

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# Coping with Emotions as You Near the End of Life

Finding out that your cancer can no longer be controlled can cause many different feelings. Some people might feel shock or fear. Others might worry about being a burden and how their death will affect loved ones. It can be hard to talk about these feelings, but know they are normal.

- Grief
- Anger
- Fear
- Regret
- Anxiety and depression
- Feeling alone
- Reflecting on your life

• Finding spiritual peace

When you find out your cancer can no longer be controlled, you might have many different feelings. Know that your feelings are completely normal. It is important to let yourself feel these emotions and grieve for what you are losing. You might feel some or all of the following emotions:

- Grief
- Anger
- Resentment
- Fear
- Regret
- Sadness
- Feeling alone
- Relief
- Calm
- Acceptance

You may also experience anxiety or depression when you have advanced cancer. While these feelings are normal, your health care team can help you cope with them. They may be able to recommend a counselor who has experience working with people with advanced cancer or prescribe medicine to help. Many people also find that talking about their feelings and concerns with family, friends, and caregivers is comforting. Learn more about grief and loss.

# Grief

It's normal to feel intense grief during the last stage of your life. You're grieving the loss of the life you expected. Or, you may have lost things already, such as the strength to get around like you used to, or the interest in doing the things you enjoy. You may feel distanced from those who are not coping well with the fact that you are in your last stage of life. Many physical and emotional losses come before the loss of life itself.

The people you love are grieving too. They know they're about to lose you. Try to talk to your loved ones about the grief and loss you're all going through. Being able to connect spiritually to something might help you and your loved ones heal after you are gone.

Talking with someone about these feelings – a partner, a dear friend, someone you trust – can help you work through them. Some people also find it helpful to talk to a

counselor or spiritual advisor. If you are receiving palliative or hospice care they will likely have someone you can talk to about your grief.

# Anger

Anger is often a part of the grieving process and is normal to feel angry. Very few people feel ready to die. It's normal to be angry if your cancer cannot be controlled. You can use your anger as fuel to solve problems or to get your needs met. But if you feel like your anger is affecting your relationships or keeping you from what you want to do, ask your cancer, palliative or hospice care team if there is a counselor you can talk to.

# Fear

Many people are afraid to die. But it might help to figure out what it is about death that you're afraid of.

- Are you worried about where you might die?
- Are you afraid of being alone when you die?
- Are you afraid of suffering or pain?
- Are you afraid of what happens after death?
- Are you afraid that your life had no purpose or meaning?
- Are you afraid of how your loved ones will cope after you die?

These are just some of the fears people have about death. Sharing your fears with loved ones and your health care team lets them help you find ways to cope and ease some of your fears. Many fears can be lessened by preparing a plan for how you'd like to spend your time as you near death.

# Regret

Some people regret or feel guilty about things they have done or not done or said. You can't change the past, but there are things you might be able to do today. Think about apologizing for the things you regret. Maybe you can ask for forgiveness or forgive others and yourself. It may be best to try to let go of the things that can't be changed.

This is a good time to <u>talk with your children</u><sup>1</sup> about the important things you want them to know. It's also good to talk to them about how to handle their feelings and the loss they will soon go through. Strengthen your relationships with loved ones. You may want to write letters to the people you love, record messages for them, or make videos they

can watch to help them remember their time with you.

# Anxiety and depression

Many people feel <u>anxious or depressed</u><sup>2</sup> as they near the end of their life. It might help to talk to someone close to you, a counselor or a spiritual advisor. If anxiety or depression is interfering with your quality of life or keeping you from doing things you enjoy, there are medicines that might help. Don't be afraid to ask for help. You want to feel the best you can so you can enjoy your time.

# **Feeling alone**

When someone knows they've reached their last stage of life, there can be a loneliness that's different from any other. It's a loneliness that happens even when you have people around you. Loneliness is common in people with cancer at the end of their life. Loneliness can affect your mental health and might make your symptoms worse.

Loneliness happens most often when someone doesn't have people around them that they feel comfortable talking with about how they feel. Loneliness can also happen when the person stops engaging in social activities that they enjoy.

Sometimes people pull back from their social networks because they are embarrassed or uncomfortable having others see how they look or feel. They might not want to burden their friends and loved ones with how they are feeling about dying or they might be having a hard time handling the reactions of their grieving loved ones.

Other times, family and friends avoid the person with cancer because they are uncomfortable seeing the changes that happen as cancer gets worse. This can make the person feel like they've been abandoned at the end of their life.

To deal with loneliness, share your feelings with your close loved ones. Or you may find that you need help from outside those close to you, such as a counselor or spiritual counselor. Your cancer care team can also provide you with support and help you get any other support you need.

Also, try to maintain your favorite social activities as long as you can. This might include letting people come and visit you. Even if you are afraid of how they will react, give people a chance. You can still set limits on what you talk about and do.

# Reflecting on your life

Consider taking time to think back over your life. You can celebrate goals you have met, people you have loved, and events that made you who you are. You may find yourself looking for meaning in your life and death. It might be helpful to talk with someone about your feelings about death, how you lived your life, and how you would like to prepare for the end. If you don't have a family member or close friend who is comfortable talking about death, talk to your cancer care, palliative care or hospice team. This may help you find some answers or improve your well-being.

# Finding spiritual peace

Some people find that spiritual peace is as important as physical and emotional comfort. If you value religion or spirituality, your faith or spiritual community may be a source of comfort now. You may want to spend some time with a faith leader, such as a chaplain, to talk about your life, faith, and what lies ahead.

You might also find spiritual comfort through nature or outside of a traditional faith community. Think about where you might find peace. For example, maybe you want to spend some time in nature at a favorite park. Ask friends or family to help you.

Spiritual experiences can bring you comfort, meaning, and peace. They can also give you a sense that your life is complete. Many people who get spiritual support have a better quality of life in their final days. If you need help finding this type of support, ask your cancer care, palliative care or hospice team. Many of these groups have a chaplain available if you don't already have a relationship with a faith leader.

# Hyperlinks

- 1. <u>www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-</u> <u>cancer.html</u>
- 2. <u>www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes/anxiety.html</u>

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