Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

Wellness along the Cancer Journey:
Nearing the End Of Life

Revised October 2015

WELLNESS ALONG THE CANCER JOURNEY: NEARING THE END OF LIFE

Goals: People taking part will understand the legal issues that need to be addressed before the end of life. They will also understand some common emotional, physical, and social issues as a person nears the end of life.

Learning Objectives:

- What is hospice care and how is it given as the end of life nears.
- How are someone's health care wishes honored if they can no longer speak for themselves?
- What are some of the legal issues that need to be taken care of at the end of life?
- What is the grieving process?

Wellness along the Cancer Journey: Nearing the End of Life

American Cancer Society Circle Of Life℠

Cancer Education and Wellness for American Indian and Alaska Native Communities

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Chapter 1: Module Overview

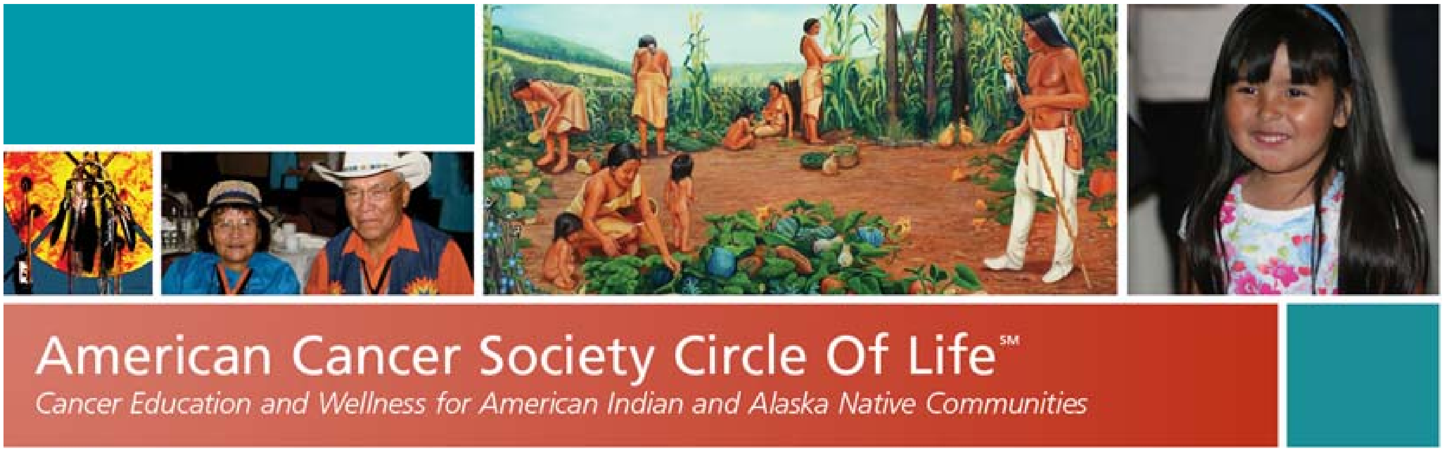
Module Overview

Many patients and family members have questions about what they might expect during the last few months of life. The information in this guide may help them understand what to expect both physically and emotionally during that time. Hopefully, it will help a person who is terminally ill to live fully and get the most out of this last phase of life.

The guide is written with the person who has cancer in mind, but it can be helpful to the people who care for, love, and support someone with advanced cancer, too. The information can also be applied to other illnesses such as heart disease, stroke, and diabetes. Use the guide to get answers to questions and concerns about this very sensitive and difficult time.

Hospice care will be discussed in this module. It is a philosophy of care that is often used near the end of life. Hospice recognizes death as the final stage of life. It seeks to allow people to be alert and pain-free and to help manage other symptoms as the end of life approaches. Most hospice care is given in the home. The goal is that a person's last days may be spent with dignity and comfort, surrounded by their loved ones.

It is important for the person with cancer to think about what kind of medical care they want as the end gets closer. A person with cancer and their family need to know that it may not be enough to just tell their family what their wishes are for their care. The person with cancer can choose the kind of treatment they get (aggressive, comfort care, or even none). They can also refuse any treatment that they do not want. The guide will talk about getting the care a person might want by using advance directives like the living will and health care power of attorney. It will also go over how and why a person might want to draft a will.



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Chapter 2: Advanced Cancer

Advanced Cancer

Group Discussion			
	True	False	Not Sure
1. Health care providers cannot assess advanced cancer.			
2. Cancer that is not considered curable may be called advanced cancer.			

Some types of cancer are more likely to spread than others. Cancer that has spread is called metastatic cancer. If cancer is not considered curable, it may be called advanced cancer. But a health care provider can't usually tell by just a physical exam whether a person already has advanced cancer.

It's also hard to know ahead of time whose cancer will spread. One way to get clues is to look at the cancer cells under a microscope. The more normal the cells look, the less likely they are to spread. Another way is to look at the size of the tumor. A larger tumor is often more likely to have spread. Also, if the cancer has spread to the lymph nodes, it is much more likely to spread to other parts of the body. Often the lymph nodes are removed during surgery to see if there are cancer cells in them. Using these tests helps the health care provider learn if the cancer has already spread.

If the cancer has not yet spread, health care providers aren't sure whether a person's cancer will spread in the future. So the health care provider does other tests to try to find the answers. Still, in many cases it's hard to predict what the cancer might do.

Signs and Symptoms of Advanced Cancer

Here we will list some of the signs of advanced cancer:

- The most telling symptom is losing energy and feeling tired (fatigued) and weak. This can get so bad that it may be hard to do daily tasks like bathing or getting dressed. People with advanced cancer often need help with these things. At some point, it gets so bad that they spend much of their time in bed.

- The person loses weight without a known reason.
- Pain may sometimes go along with advanced cancer, but not always.
- Shortness of breath is common when a cancer is growing in or has spread to the lungs.

A health care provider will ask about symptoms and do a physical exam. As part of the exam, they may look for certain signs, such as fluid in the lungs or stomach area, tumors (lumps) on or within the body, or a swollen liver.

Certain blood tests can also point to advanced cancer. Test results of liver function can be very high if the cancer has spread to the liver. Some cancers make substances called tumor markers. Blood tests can find these markers.

Pictures of the inside of the body (imaging studies) are used to look for advanced cancer, too. Many of the tests used to find advanced cancer may have been done when a person was first diagnosed with cancer.

Treatment

Advanced cancer is not likely to be cured, but it can often be treated to slow its growth. A person with cancer and their family should be clear about the goal of any treatment. They should know whether the goal is to try to cure the cancer, to let the person live longer, or to relieve symptoms. This can sometimes be confusing because the same treatments might be used for all of these reasons.

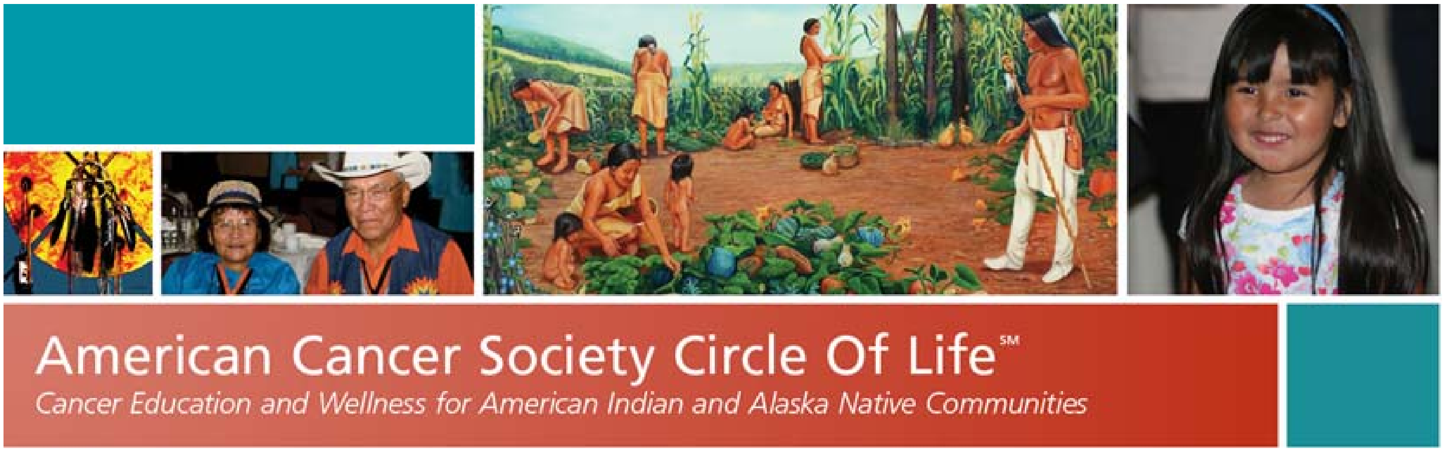
Some people believe that nothing more can be done if the cancer cannot be cured, so they stop all treatment. But often there are treatments that can control symptoms even if cure isn’t possible. Relief from symptoms such as pain, blocked bowels, and upset stomach can help maintain or improve quality of life.

Calling the Shots

A person has the right to make decisions about their treatment. Some people with advanced cancer decide that the burdens of aggressive cancer treatment are not worth the small chance of benefits. Others want to get treatment as long as there's a tiny chance it may help. Some people want to stay at home. Others choose to go to an assisted living center, a nursing home, or a hospice center. This is a very personal issue. A person should make the choices that are best for them.

They may decide after some point that they don't want any more treatment for their cancer. This may be hard for some loved ones to accept. It can help to include the family in these decisions.

Advance health care directives, which are discussed in the following section, are a way for a person to state ahead of time what kinds of treatment they want or do not want. The advance directive can put a person's wishes in writing in case they are not able to state their wishes later.



Wellness along the Cancer Journey:

Nearing The End Of Life

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Chapter 3: Nearing the End Of Life

Nearing the End of Life

Group Discussion			
	True	False	Not Sure
1. Those being treated for cancer don't have the right to make decisions about the care they receive.			
2. Care at the end of life focuses on making sure the patient is comfortable.			
3. There are many emotions that occur when someone is approaching the end of life.			

When a patient's health care team learns that the cancer can no longer be controlled, medical testing and cancer treatment often stop. But the patient's care continues.

The care focuses on making the patient as comfortable as possible. The patient receives medications and treatments to control pain and other symptoms, such as constipation, nausea, and shortness of breath. Some patients remain at home during this time, while others enter a hospital or other facility. Either way, services are offered to help patients and their families with the medical, psychological, and spiritual issues around dying.

If a person has advanced cancer, this probably means that cancer has spread from where it started to other parts of the body, or it has harmed vital tissues and organs.

At this point, a person knows that the cancer is not going away and that they probably have limited time to live. In fact, their health care provider may have told them that there is no more treatment that can really help stop the cancer and that they have only a short time left. Many people have questions about what to expect during these last months of life. The information here has been written to help answer some of the questions people ask about what to expect as the end of life nears. The time at the end of life is unique for each person. Each person will have different needs for information and support. Here we talk about some questions a person might have.

When someone learns they have advanced cancer they may feel lost and afraid. This is natural. People have many questions of all sorts, such as:

- What is going to happen to me?
- Have I done everything I should have done?
- What are the other options?
- How much longer do I have?
- How much control will I have over my life and my death?
- Will my wishes about my care be followed?
- How much pain and suffering will I have?
- What if I feel like I can’t take much more treatment?
- What am I going to do about money?
- How long am I going to have to go through this?
- How can I burden my family in this way?
- Will this be too much for my family to bear?
- What happens when I die?

Knowing that death is coming soon takes an emotional toll on the person with cancer and their loved ones. This is an emotional time, and it is hard to talk about it. Still, these issues must be addressed. Knowing these feelings are normal and expected may help a person cope with what is happening. Some of the usual emotions include the following:

Fear: People may feel afraid to die, but it can help to pinpoint what part of death they are afraid of. Are they afraid of dying alone? Are they afraid of suffering or pain? Are they afraid that they will die and there will be nothing beyond earthly life? Is there a fear that their lives had no purpose or meaning? These are some of the more common reasons that people fear death.

Trying to figure out what a person fears can help them face and manage it. It will also help others be better able to support and care for them. For example, if a person is afraid of being alone, sharing this with family and loved ones can allow them to plan to have someone there with them.

Fears may be either concrete, like pain, or abstract, like a life's purpose. Either way they are very real.

Sharing these feelings gives others a chance to provide comfort and helps a person come up with ways to cope and ease some of the fears. It can also give a person a chance to look at and deal with some of their fears in new ways.

Anger: Anger is sometimes hard to identify, but ignoring anger will not work. It is perfectly normal to feel angry about life being cut short – it's unfair and a person has a right to be mad! Very few people actually feel ready to die. But, unfortunately, anger often gets directed at those closest to us, the ones we love the most. We feel safest with these people and know they will probably accept our anger and forgive us for it. It may help to consider that anger can be directed at the disease and not at loved ones.

Also, a person can try to channel their anger as a source of energy to help them take action where it's needed. They can use it as fuel to solve problems, to become assertive, or to get their needs met. They can sing at the top of their lungs, give a speech with vigor, or tell their family some things they really want them to know. It can be helpful to re-channel anger to do things that are meaningful to the person.

Guilt and Regret: In a person's last few months of life, they might regret or feel guilty about many things. We feel regret when we think that we should have done something differently. Or maybe there are things we wish we had not done at all. We may feel guilty when we don't do what we or someone else thinks we should have done. But why hold onto guilt or regret? Worrying endlessly about these things won't make a person feel better. It won't improve relationships with family members. It won't ease the burden they are carrying. It won't make a person live longer.

Sometimes the best thing to do is for a person to decide to “let themselves off the hook” and spend their last days and months not feeling guilty about things that are out of their control. Simply let it go. A person cannot change the past, but there are things they can do today. Apologizing for those things and asking for forgiveness can help. Fix what can be fixed and try to let go of the things that cannot be changed.

This is a good time to talk with children about what is important. It is also good to talk to children about how to handle their feelings and the loss they will soon go through. A person may want to write letters to the people they love, record messages for them, make videos they can watch – give them things they can keep to remind them. Tell them who they can talk with and encourage them to be open when they are hurting. A person may feel better by spending time focusing on the children’s future, rather than feeling guilty about the past. Strengthening relationships with loved ones may also help.

Grief: It is natural for a person to feel intense grief during the last months of their life. They are grieving the loss of the life they had planned and expected. They can no longer look ahead to a seemingly “endless” future. And they may have lost many things already, such as the strength to walk or get around, or the interest in eating the things they enjoy, or maybe the ability to get together with friends. They may feel distanced from friends who cannot handle the fact that they are going to die soon. This is another loss that may cause sadness and grief. Many physical and emotional losses come before the loss of life itself.

Family and friends are grieving, too. They know they are about to lose someone they love. How can a person and those who love them find meaning in what’s happening? Try to talk about the grief and the loss of dreams everyone is going through. Being able to rise above the grief and connect spiritually to something greater than one’s self might also help. It can also give a person a break from the grief.

Talking with someone about these feelings – a partner, a dear friend, or a spiritual advisor – can help a person process these feelings so that they no longer weigh a person down. It may take many attempts before they succeed, but once they have done this they will feel a burden lifted and they can move on to the other physical and emotional tasks that make up the end of life. There are some necessary tasks at the end of life, but coming to terms with the losses is one of the most painful.

Anxiety and Depression: What does anxiety feel like? Anxiety has been described as having a nervous stomach, a shaky feeling all over, being short-tempered, a sense of dread or worry, or a fear of the unknown. It can be quite unpleasant. Anxiety can be treated through counseling or with medicine – the goal is to make a person comfortable and help them better cope with the changes that are taking place. Anti-anxiety medicines or even anti-depressants can help. Counseling can help a person change how they think about things so that they can focus on today and not worry about tomorrow. Breaking problems into smaller pieces that are easier to manage can also be a good way to handle some kinds of anxiety.

Depression is more than just feeling sad. Depression includes feeling hopeless or helpless, feeling useless, feeling sad for weeks at a time, and having no joy in any activity. These feelings are not normal, not even when life is ending. Depression can sometimes be helped with anti-depressants and counseling, or a combination of both. Managing anxiety and depression can make a big difference in how much joy a person can find in the last few months of life.

Feeling Alone: Very few people know what it feels like to know they are facing their last months of life. There can be a loneliness that is different from any other. It is a loneliness of the heart, even when a person has people around them. There may be very few people who can really talk with them in a way that helps them feel less lonely. Some of them may be experts who are comfortable talking with people at the end of life, such as hospice social workers, nurses, or other end-of-life caregivers. They may have that special gift for silence or listening when needed. Finding a few people whom a person can truly connect with is key to ease this sense of intense loneliness. The health care team may end up being a great resource in this area.

Seeking Meaning: Almost everyone wants to feel that their life had purpose – that there was some reason for being here on earth. Some people find meaning in their work. Others find that raising a family brings them the greatest sense of joy and accomplishment. It can help for someone to go through a process of reviewing their life and figuring out what their purpose in life has been. What was their special contribution to the world? What have they done to make the world a better place? How would they like the world, children, family, and friends to remember them? What were the things that are really important for their children to know about their future? It does not have to be something huge or earth-shaking. The end of life can be full of meaning and personal reflection. When a person shares their thoughts, experiences, and wisdom it is a gift that their friends and family can cherish for years to come.

The Importance of Communication

Once the health care team says, “There are no more treatments that might cure your cancer,” a person often thinks, “The ball is back in my court.” Feeling this way is a healthy approach. Rather than being a passive patient, a person may now want to start thinking about how to help others accept and enjoy the time they have left. To do this, they will need complete and honest information. Telling the health care provider exactly what they want to know and getting the information is an empowering step.

Some people are not willing to accept “no more treatment.” They may find that they want to get a second opinion and find out if there are ways to actively fight the cancer. That’s OK! It is their choice, and they have to be comfortable with the decisions. Making the medical team and loved ones part of the decision-making process will help things go more smoothly.

If a person opts for more treatment in spite of a health care provider’s recommendations, it is helpful if they explain the decision to the people on their cancer care team. Even if they do not understand or agree, a person still must pursue their own sense of what is right for them. As long as they have fully explored all options, friends and family will most likely be supportive. Keep in mind that no decision is forever. A person can change their mind about treatment at any time.

Building a Support Network

Some people may have never needed a large support network. Maybe it is not easy for them to reach out to others, especially when they may feel they do not have a lot to offer in return. Even so, there may be people who want to give support through this time. They may be waiting for someone to tell them what to do and how to help.

If friends and family are not available to support the person with cancer, there are often others who are. Online networks of support are also available, such as the American Cancer Society Cancer Survivors Network®. The local health care community may have support groups, and the religious community may have people who simply enjoy serving others. Hospice teams offer support resources for people with cancer.

It is unrealistic, and maybe even unhealthy, to try to get through this time without supportive, loving people. This is the time to reach out and enjoy people and the gifts they have to offer.

Spouses and Partners

Cancer takes up a great deal of time and energy. Cancer and end-of-life care places a huge physical and emotional burden on those closest to a person. Spouses or partners may be either a person's greatest ally or the biggest disappointment as a source of support. There are obvious reasons for this. Sometimes a spouse or partner is dealing with their own emotions and yet feels a lot of pressure to come through and meet every need the person has. Some people just can't handle that kind of pressure and may withdraw under these circumstances. They may pull away at a time when a person feels they need them more than ever. This can be very painful to the person with cancer.

On the other hand, a partner or spouse can be right there, and that can be painful, too. It can be very troubling for a person to know everything their spouse or partner is feeling and thinking and to see the pain they are going through. Sometimes spouses or partners worry about this and try to protect each other from the pain they are both going through. But when this happens, honesty is sacrificed. Walls are built up, topics are avoided, and relationships can become strained and uncomfortable.

The death of a spouse is one of the most stressful events a person can experience. Anticipating this loss every day and living with these feelings is even more stressful. If at all possible, spouses should try to talk to each other about what they are feeling. They will probably find that they are both going through some of the same emotions. Simply let each person say what they feel. Don't try to fix the feelings. Be aware of them and express love and care for each other. This is another chance to try to make any past wrongs right and for spouses to comfort each other. This doesn't mean that spouses won't get angry and frustrated with each other, but try to let the small arguments go. Focus on the good times, happy memories, and the times of mutual support.

Alone Time

It is also important for spouses and family members to allow each other personal space and private time. They can assure each other that they still love each other, but it's OK if people need some time to be alone. This is a common need as a person faces the end of life. No one can be with someone 24 hours a day. And a person cannot squeeze a lifetime into 2 months. Make the most of each day, be grateful for it, and greet the next one as a new chance to enjoy each other.

Helping Taking Care of a Spouse or Partner

A person may need to talk to their spouse or partner if they are worried about the burden of caretaking they are under. Ask they are managing it. A caregiver may show signs of emotional and physical stress, such as depression, headaches, trouble sleeping, or weight loss or gain. Remind family members to take care of themselves. Ask other friends or family members to help out if there is too much for one caregiver to do.

Sex and Intimacy

At this stage of dealing with cancer, it may be hard to be as sexually close as in the past. A person may be tired, in some pain, or simply not interested in sex. But they can still keep physical contact in their relationship and share intimacy. Partners should talk about their needs; about physical closeness and affection, and they want to feel close but they might not feel like having sex. At this time simply touching, hugging, and holding hands may feel more intimate than other forms of physical contact.

Family

Cancer is a family illness. Loved ones are hurting, too. Each member of a person's family is working through their own emotional responses to the idea of losing their loved one. They need love and understanding. Though it may seem impossible, there are things that a person can do to help them manage better.

A person can help adult family members by being open about their cancer, the amount of time they have been told they have left, and any other needs they may have. It also helps to share with them what to expect in the dying process, and how to manage symptoms that may happen. A person can explain to family that they are open to discussion and that they are willing to talk about anything. A person can explore their thoughts and feelings with them.

A person can also tell family members that although they are open to talking, there may be times they do not feel like it and they will let them know when that is. It is better to not try to put on an act and pretend to be happy at times when a person does not feel happy. This doesn't mean a person is not OK – it may just mean they are feeling a tired, sad, or low on energy.

A person can tell family that they will be as honest with them as they can be and would like the same from them in return. Giving them information about what is expected to happen in the future will help them be prepared. Sharing information about plans that have been made or need to be made can be helpful. Adult children may be juggling their own children, jobs, and care taking. It is a stressful time. Sometimes they may not be able to do everything expected of them. Open, honest communication will help everyone support each other through this time.

What are some ways that caregivers can provide emotional comfort to the patient?

Everyone has different needs, but some emotions are common to most dying patients. These include fear of abandonment and fear of being a burden. They also have concerns about loss of dignity and loss of control. Some ways caregivers can provide comfort are as follows:

- Keep the person company – talk, watch movies, read, or just be with the person.

- Allow the person to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen.
- Be willing to reminisce about the person's life.
- Avoid withholding difficult information. Most patients prefer to be included in discussions about issues that concern them.
- Reassure the patient that you will honor advance directives, such as living wills.
- Ask if there is anything you can do.
- Respect the person's need for privacy.

Adapted from National Cancer Institute, http://www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet#q5 (June 23, 2015).

Children and Teens

It is natural to want to protect children from the harsh reality that a loved one will not be here in a few months. Professionals who work with families would strongly encourage people not to "protect" children in this way. Children, even the youngest ones, also need to be prepared for the future. Honesty is important. Children can usually sense changes or stress in the household and know when something is wrong. Many times what they imagine is far worse than anything that's really happening.

Children naturally focus mainly on themselves. And they often think they caused the problems they sense in those around them. They may feel guilty because they believe that something they've done caused the cancer to grow. It is up to the person with cancer to assure them that they had nothing to do with it. The child may need to hear this over and over from adults they trust before they can believe it.

Give children information in small doses, in language they can understand. A person can explain that cancer is a serious illness, not like a cold or the flu. The person with cancer can let the child know that they will keep fighting, but health care providers have given them all the treatments they can to fight the cancer. A person can invite the child to ask questions, and give simple honest answers.

It can help to share some good times with children before the cancer takes over. The person with cancer can choose activities they can still do with the child, and plan to do them at times of the day when they have more energy.

Children also need to know what will happen when a parent is no longer there. A person should explain in some detail what will happen when they are gone; how the children will be cared for and by whom. This will be a hard discussion. It is a sad time, but they need to know these things. Tell the child it's OK to ask any question they may have.

Children may need help to identify and talk about their feelings. Sometimes it helps to tell the children about people and places they can go to when they are sad. Make sure they know that their feelings are normal. It can be good to have counseling or go to a support group to help them through this.

Encourage children to help with some physical tasks, such as getting things for the person with cancer, or reading to them. This way they do not feel so helpless or in the way. It is easy for busy adults to ignore or push children out of the way without meaning to do so. These moments are precious, and they will become fond memories the family and the child can cherish in the future.

Friends

Some friends respond as expected – they are warm, supportive, and available. Other friends may seem to be more awkward. They may act as if they don't know what to say or do and seem to have a hard time being “normal.” Sometimes a person can talk to their friends about their discomfort. They can explain they are the same person and would like to spend some of their remaining time with them, if the friends are willing to do that. What a person with cancer is going through may cause loved ones to think about the fact that they, too, will die. Because this is not a pleasant thing to do, some people may avoid spending time with a person with cancer.

Support Groups

Taking part in a group can give a person a sense of belonging. It also gives them a safe place to talk about fears and emotions that they may feel uncomfortable talking about with other people. Group involvement has been shown to ease isolation and reduce stress.

There are many types of support groups, both formal and informal. Some of the formal groups are set up for caregivers, others for people with certain types of cancers, or people of certain ages. There are bereavement groups for adults and even some for children who have lost a loved one to cancer. In a support group, people are coping with the same problems and issues. The encouragement and understanding found in a group of people sharing such a profound life experience can be priceless. Some groups last for only a given number of weeks or months, and others are open ended.

A person may find it hard to go out to meetings in their last weeks of life. Some of the more informal groups, such as a neighborhood group of friends or a church group, may be willing to meet a person in their home. Internet support groups may be a good option for people who are homebound and able to use a computer. Hospice agencies are often involved in the last months of life. They offer the help of staff members who can give specific types of support around specific needs. For example, there are staff members who can help a person with emotional support. There are also those who focus on spiritual concerns. Clergy or other spiritual leaders are often willing to make home visits to people in the last months of life.

Activity

During a stressful illness such as cancer, people often become anxious. Below are some of the symptoms of serious anxiety. Please review the list below and check yes or no to each symptom.

Symptom	Yes	No
Your body is constantly tense		
You have racing thoughts.		
You are unable to control how much time you spend worrying.		
You have frequent aches and pains that can't be traced to physical illness.		
You are irritable most of the time.		
You find yourself trembling or shaking.		
You have noticed a racing heart, dry mouth, excess sweating, or being short of breath,		
You feel the worst will happen (even though no one has told you that).		

Some people notice that they have one or two of these symptoms for a short time after they learn they have cancer. If these symptoms keep bothering a person, they might take this list with their answers and talk it over with their health care provider. Anxiety can often be managed and treated so people enjoy life again. However, it is important to see a health care provider if a person has strong feelings of anxiety, fearful thoughts, or can't accomplish ordinary, daily activities.

After seeing a health care provider, a person may feel better quickly because anxiety can be treated. People are often surprised at how much better they feel, and wonder why they waited so long to get help.

Story of Hope

"I first got involved with cancer when my mother was diagnosed with lung cancer. By the time she was diagnosed, she was told she has two years to live, and I'm the eldest of nine. During those two years, she and I and a lot of our family were able to do a lot of things that she wanted to do and so with some respects being told that you have a certain amount of time left in your life is pretty much of a blessing, because then you can do all the things that you want to do before your time."

- CeCe Whitewolf, Confederated Tribes of Umatilla Breast Cancer Survivor

(Clark, R., (Producer) & Whitewolf, C. (Artist). (2007). *Survivor Video Vignettes: Do the Things You Want to Do Before You Die.* [Web]. Retrieved from http://www.natamcancer.org/vignettes/cc3-palliative.html)

Key Messages

- Be open about fears. Express fears to family, friends, or a spiritual guide. Write in a journal, dance, sing, or be expressive in a way that feels good.
- Focus on activities that bring joy. Get out of the house if possible.
- Anxiety can be treated so talk to a health care provider about this.*

American Cancer Society Circle Of Life℠

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Chapter 4: Hospice Care

Hospice Care

Group Discussion			
	True	False	Not Sure
1. There is no difference between palliative care and hospice care.			
2. Palliative care begins at diagnosis and continues during cancer treatment and beyond.			
3. Hospice care begins one year prior to the end of life.			

Palliative care is different from hospice care. Both palliative and hospice care share the same principles of comfort and support, but palliative care differs because it begins at diagnosis and continues during cancer treatment and beyond. Palliative care addresses the emotional, physical, practical, and spiritual issues of cancer during treatment and at the end of life when a person may be in hospice.

How is palliative care given at the end of life?

Making the transition from treatment that intends to cure cancer to end-of-life care is a key part of palliative care. Near the end of life, palliative care is often used alone in hospice settings. The hospice team can help patients cope with the different thoughts and emotional issues that arise, such as worries about leaving loved ones behind, reflections about their legacy and relationships, or reaching closure with their life. In addition, palliative care can support family members and loved ones emotionally and with issues such as when to stop trying to treat the cancer, grief counseling, and transition to hospice.

Hospice is a program designed to give supportive care near the end of life. The right time for hospice care is when treatment aimed at a cure is no longer helping someone.

Hospice sees death as the natural, final stage of life. It seeks to manage a person's physical and emotional symptoms. Its focus is on quality of life, rather than its length.

Hospice programs offer family-centered care. They involve the person with cancer and family in making decisions. Hospice care is usually given in the home. But there are a few hospitals that offer hospice care and some private hospice centers. Hospice care is also offered in some nursing homes.

In a hospice program, a team will usually care for the person with cancer. The team will have a medical director who is a health care provider, a nurse, a nurse's aide, a social worker, and a chaplain. In most cases, the person's own health care provider will also play a role.

It can be hard to decide to start hospice care. In general, it means someone is ready to stop treatment aimed at curing the cancer. A person can only enter hospice if they are expected to live about six months or less if the illness runs its usual course. But sometimes people in hospice can live longer. Together, the person with cancer, family, and health care provider decide when hospice care should begin. Many professionals in the field notice that many people are referred to hospice within days of death. There is much that a hospice program can do to help a person's quality of life, but it can help more if they have at least a few weeks to work on it.

Most hospice programs do not allow someone to get treatments such as chemotherapy, radiation, transfusions, or IV nutrition. An honest talk with a health care provider can help a person decide if that is the right thing to do. Ask whether any treatment the health care provider suggests offers hope for a cure. If a cure is not possible, will the treatment prolong life or relieve symptoms?

A person should think about hospice if their health care provider can't assure them that treatment will meet any of these goals. A hospice program may give the best chance of controlling symptoms and providing quality of life. Most experts in palliative care observe that people enter hospice programs too late to get their full benefit.

Choosing Hospice Care

Hospice care puts a person and their loved ones in the care of experts at the end of life. The goal of hospice care is to help someone live their last days as alert and pain-free as possible. Hospice care aims to manage symptoms so that a person's last days may be spent with dignity and quality, surrounded by their loved ones. Hospice affirms life and neither hastens nor postpones death. Hospice care treats the person rather than the disease; it focuses on quality of life. It provides family-centered care, involving the person with cancer and their family in all decisions.

This care is planned to cover 24 hours a day, seven days a week. Most hospice care in the United States is given in the home, with a family member or friend serving as the main caregiver. If a person wants home hospice care, a caregiver must be in the home with them 24 hours a day.

Hospice care is used when a person can no longer be helped by treatment that aims to cure. The person, their family, and their health care provider decide together when hospice services should begin. If a person gets better or the disease goes into remission, they can be discharged from the hospice program and return to active cancer treatment if they wish. Hospice care may be resumed at a later time if needed.

Making the choice to get hospice care should not be viewed as a last resort. The benefits that a person and their family can get from hospice care are very valuable. Through hospice care a person will get help to put their affairs in order, say their good-byes, and spiritually prepare for death in a way that promotes dignity and comfort. The family will be fully supported through the dying process and helped through grief and bereavement.

Even though it is common to hear that someone must expect to have six months or less to live, other standards are also used to decide if a person with cancer can enter hospice. In most cases, a person must have widespread, aggressive, or progressive disease. This means worsening symptoms, worsening lab values, and/or signs of metastasis (the spread of cancer cells to distant areas of the body). They must also be unable to work or do certain things. Finally, they must have either refused life-prolonging therapy or have been getting worse in spite of treatment.

Who Gives Hospice Care and What They Do

There are things about hospice care that make it different from other health care. Hospice care is mainly palliative care. Palliative care is treatment to relieve physical and emotional symptoms. It focuses on comfort and increases well-being. Hospice staff members are specially trained to help a person with cancer and their loved ones through this very difficult time. The knowledge and experience they can share can help a person to have the very best quality of life right up until the very end.

Hospice care uses a health care team that often consists of:

- Oncologists (cancer specialists)
- Primary care physicians
- Physicians who specialize in palliative care
- Nurses

- Social workers
- Pain specialists
- Physical or occupational therapists
- Dietitians
- Pharmacists
- Counselors
- Spiritual or faith-based advisors

Each team member offers support based on their special areas of expertise. Together, they give complete palliative care. Their goal is to improve a person's quality of life by taking care of the following:

Pain and Symptom Control: The goal of pain and symptom control is to help a person to be comfortable while allowing them to stay in control of and enjoy their life. This means that side effects are managed to make sure that they are as free of pain and symptoms as possible, but still alert enough to enjoy the people around them and make important decisions.

Spiritual Care: Hospice care also tends to the spiritual needs of a person and their family may have. Since people differ in their spiritual needs and religious beliefs, spiritual care is set up to meet specific needs. It may include helping them to look at what death means, helping to say good-bye, or helping with a certain religious ceremony or ritual.

Home Care and Inpatient Care: Even when hospice care is based in the home, a person may need to be admitted to a hospital, extended-care facility, or an inpatient hospice facility. Hospice can arrange for inpatient care and will stay involved in with a person's care and with their family. A person can go back to in-home care when they are ready.

Respite Care: While a person is in hospice, their family and caregivers may need some time away. Hospice care may offer them a break through respite care, which is often given in up to five-day periods. During this time a person will be cared for either in a hospice facility or in beds that are set aside for this in nursing homes or hospitals. Families can plan a mini-vacation, go to special events, or simply get much-needed rest at home while their loved one is cared for in an inpatient setting.

Family Conferences: Through regularly scheduled family conferences, often led by the hospice nurse or social worker, family members can stay informed about their loved one's condition and what to expect. Family conferences give everyone a chance to share feelings and talk about what they expect. It can also help the family learn about death and the process of dying. Family members often find great support and stress relief through family conferences. Conferences may also be informal as the nurse or nursing assistant talks with a person and their caregivers during their routine visits.

Bereavement Care: Bereavement is the time of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to loved ones through visits, phone calls, and/or letter contact, as well as through support groups. The hospice team can refer family members and care-giving friends to other professional care if needed. Bereavement services are often provided for about a year after a loved one's death.

Volunteers: Hospice volunteers play an important role in planning and giving hospice care in the United States. Volunteers may be health professionals or lay people who provide services that range from hands-on care to working in the hospice office or fundraising.

Staff Support: Hospice care staff members are kind and caring. They communicate and listen well, and are interested in working with families who are coping with a life-threatening illness. They are usually specially trained in the unique issues surrounding death and dying. Yet because the work can be emotionally draining, it is very important that support is available to help the staff with their own grief and stress. Ongoing education about the dying process is an important part of staff support.

Coordination of Care: The hospice team coordinates and supervises all care seven days a week, 24 hours a day, seven days a week. This team is responsible for making sure that all involved services share information. A person with cancer and their caregivers are encouraged to contact their hospice team if there is a problem, anytime, day or night. There is always someone on call to help with whatever may arise. Hospice care assures people that they are not alone and help can be reached at any time.

Where Hospice Care Is Provided

Hospice care can be given in:

- Someone's home
- A hospital
- Nursing home
- Private hospice facility
- Inpatient hospitals
- Outpatient clinics
- Skilled nursing or assisted living facilities

Finding Hospice Care

Finding the hospice program that best meets a person's needs may take some research, but it will be time well spent. It is important that a person and their family do this while they have the strength and ability to do so. Quality of care, availability of needed services, the types of services covered, staff training and expertise, and insurance coverage are all things to think about. Most communities have more than one hospice provider. Ask around about others' experiences with hospices. Other resources are listed at the end of this module, but here are some other ways to start the search:

> *Local Resources:* A health care provider or hospital discharge planner can help find hospices in the area. Hospice care providers are often listed in the phone book. A person may be able to contact the local American Cancer Society, an Agency on Aging, a local United Way chapter, the Visiting Nurse Association, or a place of worship for information on hospices nearby.
>
> *State Resources:* A person can contact their state's hospice organization or its department of health or social services to get a list of licensed agencies. The state health department oversees certification of hospice services. Certification qualifies them to be paid by Medicare and, in some states, also from Medicaid. Check the blue pages of the phone book for other state resources in the area.
>
> *National Resources:* National organizations that address hospice accreditation, treatment, and patient advocacy are listed in Appendix D.

Paying for Hospice Care

Home hospice care usually costs less than care in hospitals, nursing homes, or other institutions. This is because less high-cost technology is used and family and friends provide most of the care at home.

Medicare, Medicaid, the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care plans may pay for hospice care. Along with this, community and memorial donations and foundation gifts allow many hospices to give free services to people who can't afford to pay. Some programs charge people based on their ability to pay. To get payment from Medicare, the agency must be approved by Medicare to provide hospice services.

To qualify for the Medicare hospice benefit, a health care provider and the hospice medical director must certify that a person has less than six months to live if the disease runs its normal course. The health care provider must re-certify someone at the beginning of each benefit period (two periods of 90 days each, then an unlimited number of 60-day periods). The person signs a statement that says they understand the nature of the illness and of hospice care, and that they want to be admitted to hospice. By signing the statement, the person declines Medicare Part A and chooses the Medicare hospice benefit for all care related to their cancer. The person can still receive Medicare benefits for other health problems. A family member may sign the statement if their loved one is unable to do so.

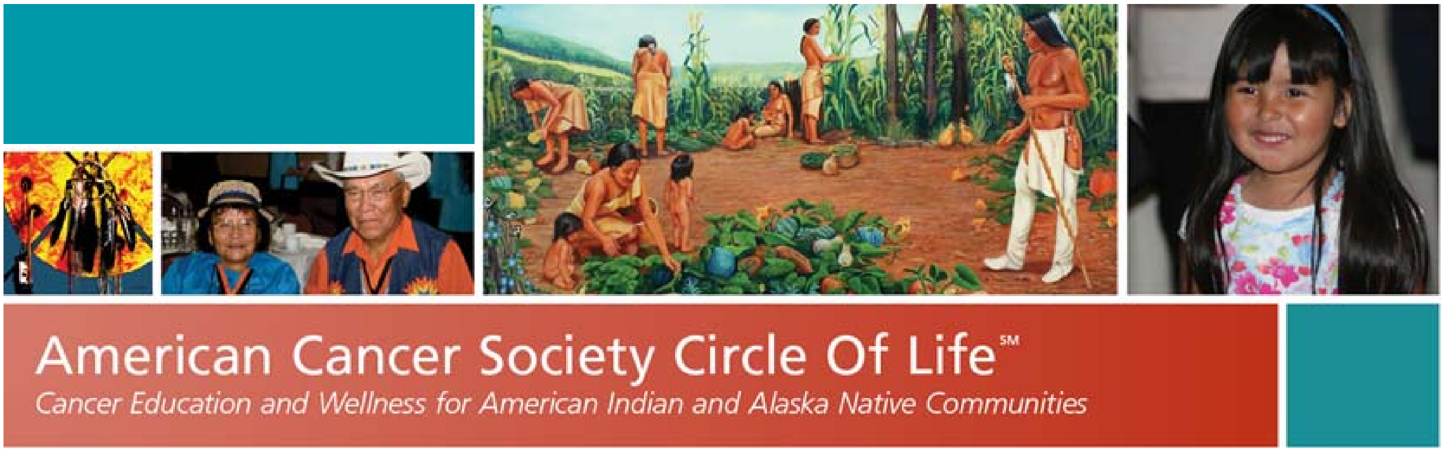
Medicaid Coverage: In 1986, laws were passed to allow states to develop coverage for hospice programs. Most states have a Medicaid hospice benefit, which is patterned after the Medicare hospice benefit.

Private Insurance: Most private insurance companies include hospice care as a benefit. Be sure to ask about insurance coverage, not only for hospice, but also for home care.

Private Pay: If insurance coverage is not available or does not cover all costs, a family can hire hospice providers and pay for services out of pocket. Some hospices are able to provide services without charge if a person has limited or no financial resources.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities



Wellness along the Cancer Journey:

Nearing the End Of Life

Revised October 2015

Chapter 5: Advanced Directives

Advance Directives Overview

Group Discussion			
	True	False	Not Sure
1. A person's health care wishes can be honored through legal means.			
2. Advance directives require patients to have treatment.			
3. There is only one type of advance directive.			

An *advance health care directive* or *advance directive* is a kind of legal document that tells a health care provider a person's wishes about their health care. Advance directives are only for times that a person can't speak for themselves. They do not affect a person's type or quality of health care while a person can voice their own decisions. Advance directives take effect when a person can no longer speak for themselves.

There are several types of advance directives. They can be general, with very few directions about care, such as a basic *power of attorney for health care.* This kind of directive usually just names a substitute person (agent or proxy) to make decisions for a person who is unable to do so.

Advance directives can also be very detailed. Some *living wills* clearly outline the different types of life-sustaining treatments a person would accept or refuse in certain situations. There are other types of advance directives that are limited to certain situations, such as organ or tissue donations or your wishes not to be revived if your heart or breathing stops.

No matter which kind of directives a person uses, **no one will be able to control their money or other property** based on an advance health care directive. It may also help to know that a person can also change or revoke (take back) their directives at any time.

Advance Directives and Informed Consent

Adults have the right to control their medical treatment as long as they are mentally able to do so. They can choose which course of treatment they would like from those the health care provider offers. They can choose the kind of treatment (aggressive, comfort care, or even none), and can refuse any treatment that they do not want. This right is generally called *informed consent*.

Informed consent means that the doctor or nurse explains the purpose, benefits, risks, and alternatives of the treatment before a person decides whether to get it. In most cases, treatment can be given only if the patient agrees to it. Still, this right is not absolute. For example, if a person needs immediate or emergency care, a health care provider may go ahead with treatment even if the person can’t take in information and agree (consent) to be treated at that moment.

It’s also generally accepted that a competent (mentally able) adult may refuse medical testing or treatment if they understand the likely outcomes of refusing. This is sometimes called *informed refusal*. A competent adult patient may also ask that treatment be stopped, even if it means they will die as a result.

Sometimes, family members make medical decisions for spouses, parents, or adult children who cannot speak for themselves. Whether this type of informal arrangement is allowed depends on the medical provider and which state you live in. Many states have passed laws that say which family members (in a listed order of priority) may act on behalf of a person who cannot speak for themselves. But if there is any disagreement between family members it can complicate and delay decision making.

Even though others may be able to make health care decisions without an advance directive, these documents can give a person more control. An advance directive offers a better chance that a person’s wishes will be carried out at a time when they can’t speak for themselves.

Types of Advance Health Care Directives

General information about different advance health care directives, like living wills, durable powers of attorney, letters of instruction, and others like these will be reviewed here. They apply only to health care decisions and do not affect financial or money matters. Because the laws vary by state, it helps to find out about what a state requires. Please see Appendix A for frequently asked questions about advanced directives.

The types of advance health care directives vary based on state laws and a person's preferences within these states' legal requirements. The two most common types of advance directives are the *living will* and the *durable power of attorney for health care*, which is sometimes called the *health care power of attorney* or *health care proxy*.

- The living will covers a list of health care decisions when a person is *permanently unconscious* or is *terminally ill* or and can no longer voice decisions.
- The durable power of attorney for health care allows a person to name an agent or proxy (substitute person) to make their health care decisions if the time comes when they are unable to do so.

Advance health care directives can also include extra guidance about making health care decisions. For instance, a directive lets a person say when they do not want to be *resuscitated* or if they want to donate organs or tissue. (Resuscitation means an attempt by medical staff to re-start the heart and breathing, such as CPR. In some cases it may also include devices that try to prolong life, such as breathing machines.)

Advance directives usually let a person include instructions for other situations, too, such as when they may be unconscious for a short time. Some advance directives allow instructions if the person is impaired by Alzheimer's disease or something like it.

If a person does not have written advance directives, some states recognize spoken (oral) advance directives as legal. A person may make a properly witnessed statement that must then be written by someone who heard it.

If a person expects problems with mental illness, an advance directive can be used to outline their health care wishes. The directive can be used if they later become seriously mentally ill and can't make health care decisions. This is called a *mental health care directive* or *psychiatric care directive*.

Living Will

A living will is a document designed to control future health care decisions only when a person becomes unable to make decisions on their own. State laws vary, but most allow health care providers to stop trying to prolong life in the case of terminal illness or permanent unconsciousness. If a person has hope of recovery, the living will generally does not apply.

A living will describes the conditions in which an attempt to prolong life should be started or stopped. It further lists the type of medical treatment the person would want in these situations. This applies to treatments such as dialysis, tube feedings, or artificial life support.

The living will is a formal legal document that must be written and signed by the person. Some state laws contain a model form. For most states the form is not required, but others require that their form be used. Most laws require the living will to be witnessed and notarized. Usually, the witnesses cannot be spouses, potential heirs, an attending physician, or employees of the patient's health care facility.

There are many things to think about when writing a living will. These include:

- The use of equipment such as dialysis (kidney) machines or ventilators (breathing machines)
- "Do not resuscitate" orders (instructions to not use CPR if breathing or heartbeat stops)
- Whether to have fluids by vein and/or nutrition (tube feeding into the stomach) if someone cannot eat or drink.
- Whether to have food and fluids even if the person is not able to make other decisions

- Whether to have treatment for pain and nausea or other symptoms, even if the person is not able to make other decisions (this may be called "comfort care" or “palliative care”)
- Whether a person wishes to donate organs or other body tissues after death

It is also important to know that choosing not to have “aggressive medical treatment” is different from refusing all medical care. A person can still get antibiotics, nutrition, pain medicines, and other treatments, even if they have chosen not to have “aggressive medical treatment.” It’s just that the goal of treatment is comfort rather than trying to cure the cancer. It’s important that a person make it clear exactly what they want and don’t want.

A person may revoke (end or take back) a living will (or any other type of advance directive) at any time. It is important to know that a few states will automatically void the living will after a certain number of years.

There is no general agreement for recognizing living wills from other states. If a person spends time in more than one state, they should create separate living wills. Some people may find a way to be sure that their living will meets the requirements of all the states they spend a lot of time in.

A living will is more limited than a health care power of attorney (discussed later). The living will generally applies only when a person is terminally ill or permanently unconscious and unable to make their wishes known. It also only gives written instructions about certain things that might happen and does not cover every health care situation that could come up. With most types of living wills, a person can’t choose an agent or proxy to make decisions for them, and no one is appointed to be sure that their wishes are carried out. That’s why most people need a health care power of attorney also (discussed below).

Durable Power of Attorney for Health Care

A durable power of attorney for health care is also called a health care power of attorney. It is a legal document in which a person chooses an agent (who may also be called a proxy or substitute) to make all health care decisions if they become unable to do so. If a person names an agent, that person can speak with health care providers and other caregivers and make decisions on your behalf. The agent or proxy decides which treatments or procedures to do or not do. If a person's wishes in a certain situation are not known, the agent will decide based on what they think would be wanted and what they consider to be the person's wishes. But some states do restrict the ability of the agent to carry out some requests. For example, a few states do not allow an agent to stop artificial nutrition (feeding) and giving fluids.

The person named as the proxy or agent should be someone who can be trusted to carry out a person's final wishes. It's also important to choose a person who knows the patient well. Most people choose their spouse or a close friend or family member who knows their situation and has a good idea of what they would want. If needed, the agent must be able to do this in a time of great stress, uncertainty, and sadness. Talk to them and be sure that they're comfortable in this role. Be sure to discuss your wishes in detail with that person. It is also a good idea to name a back-up person to be the agent in case the first choice becomes unable or unwilling to do their job. (Some states ask for this back-up agent, or successor, on the health care power of attorney form.) The law does not allow the agent to be a health care provider, or other person providing health care, unless that person is a close relative.

State laws that let a person choose a proxy or agent usually require that the request be in writing, signed by the person choosing the agent, and witnessed. In many cases, the agent also signs the document. Some states have a special form for this.

Just like with living wills, state laws vary. For instance, some states will automatically void a health care power of attorney in certain cases when marital status changes. It is important that a person get the information that applies to their state, and any forms that the state requires.

The Five Wishes and Directives Like It

Advance directives vary a lot by state, but many states let a person include instructions for certain situations. For example, the Five Wishes form, which is legally recognized in 42 states as of 2015, asks whom a person would want to make their health care decisions if they could not. It also asks about their choice of medical treatment, how they want to be treated, instructions on comfort care, and final expressions or wishes for family and friends. Visit agingwithdignity.org for Five Wishes forms and others. Make sure the state accepts the form if you want it to be legally binding. In order to be sure the information is helpful to family and loved ones, be sure that the form outlines the exact wishes and choices. Even if it isn't legally binding in a particular state, it might help family and loved ones make decisions the way the person wants.

Do Not Resuscitate Orders

If a person is in the hospital, they can ask their health care provider to add a Do Not Resuscitate or DNR order to their medical record. They would ask for this if they didn't want the hospital staff to try to revive them if their heart or breathing stopped. But remember that an inpatient DNR order is only good while a person is in the hospital. Outside the hospital, it's a little more difficult.

Some states have an advance directive that is called a *Do Not Attempt Resuscitation (DNAR)* or special *Do Not Resuscitate (DNR)* order for use outside the hospital. The non-hospital DNR or DNAR is intended for emergency medical service (EMS) teams that answer 911 calls. EMS teams are usually required to try to revive and prolong life in every way they can. Even though families expecting a death are advised to call other sources for help when the person with cancer worsens, a moment of uncertainty sometimes results in a 911 call. This can mean unwanted measures that prolong death. The non-hospital DNR or DNAR order offers a way for people to refuse the full resuscitation effort in advance, even if EMS is called. It must be signed by both the person with cancer and the health care provider.

Keeping Advance Directives Available

All these important documents should be kept in handy, easy-to-find places so that someone else can find it if a person is in the hospital and needs it. Make sure that family members have copies and that others know where the advance directive is kept. Be sure it is clearly marked.

See Appendix B for a list of instructions on how to write an advance directive.

Circle Of Life: Cancer Education and Wellness

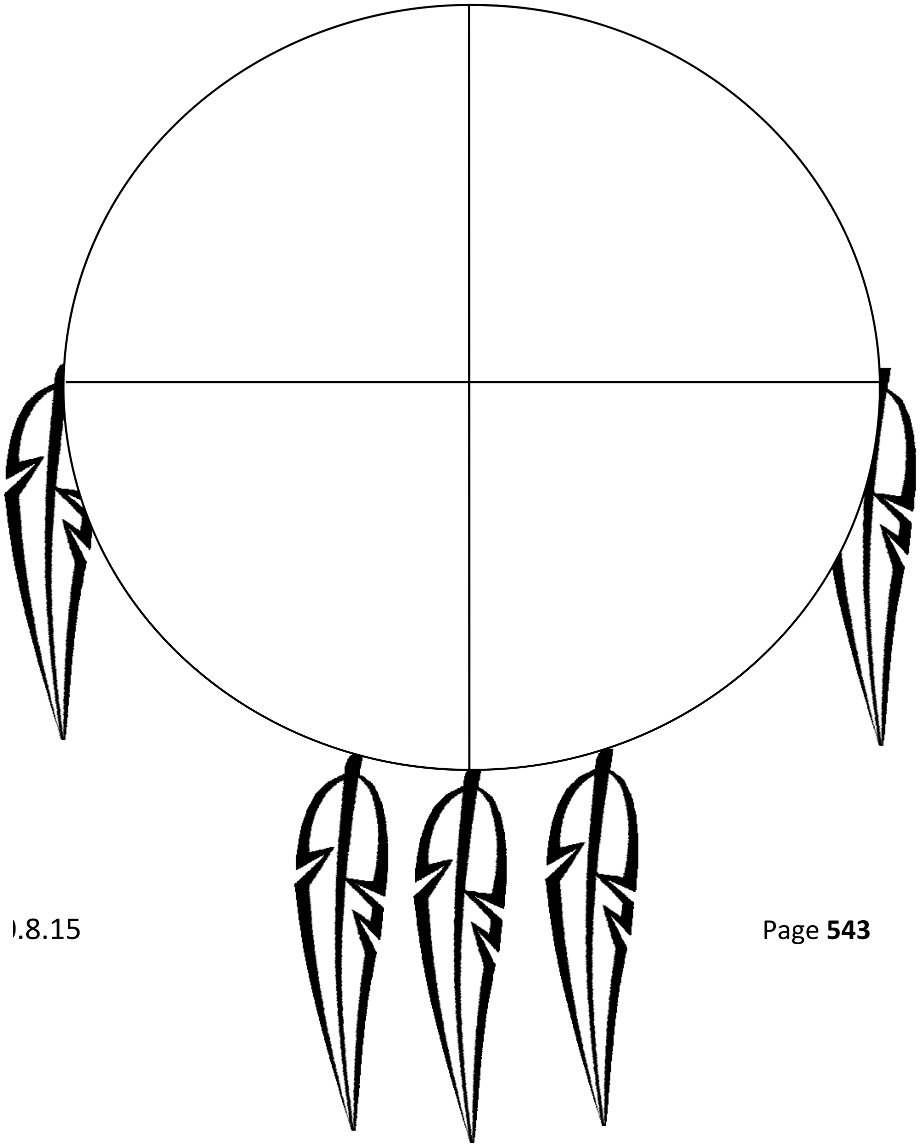
for American Indian and Alaska Native Communities

Activity

Consider each question below and when you are ready, write your answers as best as you know them at this time in each section of the shield.

Who do you want to make decisions for you when you are no longer able to?

What measures do you want to try and prolong your life?



As you reach the end of your life, do you want to die at home? Would you like hospice care?

After you die, are you willing or unwilling to donate your organs or tissues to others who need them to live?

Story of Hope

"I think at some point you've gotta reconcile that death is possible, of course death is inevitable for all of us down the road but when you get a diagnosis of cancer I think you've gotta really decide, do you really want to fight this, because if you decide you don't wanna fight it, I think you really can die faster but I determined somewhere early on that I really wanted to live and I was I believe about 43 at that time, and you know they say, life begins at 40 a lot of interesting things were going on in my life."

– Angela Russell, Crow Breast Cancer Survivor

(Clark, R., (Producer) & Russell, A. (Artist). (2007). *Survivor Video Vignettes: Perceptions of Death.* [Web]. Retrieved from http://www.natamcancer.org/vignettes/angela-palliative.html)

Key Messages

- An advance directive allows a person to state what they want to happen if they become unable to make their own medical decisions.
- The time to create a living will or durable power of attorney is before one is needed!
- A person should make sure family members and trusted friends know their end-of-life wishes and where they keep all legal documents that state these wishes. Advance health care directives should not be locked up in a safe.

American Cancer Society Circle Of Life℠

Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness along the Cancer Journey:
Nearing the End Of Life
Revised October 2015

Chapter 6: Overview of Wills

American Cancer Society®

Overview of Wills

Group Discussion			
	True	False	Not Sure
1. A will needs to be updated every year.			
2. Birth of children and other life events are important when creating a will.			

A will is a written legal document in which an individual states what their wishes are for his or her property/estate after death, who they want to carry out (execute) the conditions of the will, and who should have custody (guardianship) of their minor children.

Some people think that wills are only for rich people. But just about everyone who has assets or properties (like bank accounts or other funds, a car, a home, or land) needs a will to be sure that those things go to the people they choose.

There are several requirements for drawing up a will. A person has to be of legal age (18) and of sound mind. A will must be also signed and witnessed by at least two people.

A qualified health care provider should be consulted before preparing a will if a person has had mental illness or if a disease may be affecting a person's decisions or thoughts. Consulting a health care provider is important because it will help be sure of a person's mental competence. This will be useful should the will be challenged later based on mental incapacity.

If a person is married it is important that both they and their spouse draft wills in case one spouse dies before the other. Usually the other spouse is named as the primary beneficiary (the person who gets most of the assets belonging to the one who died) and a substitute person should be identified if both spouses pass away at the same time. This should be done even if all the assets are mainly in the name of one spouse.

If a person is living with someone but not married and they want their significant other to benefit from the estate, it is even more important to prepare a will. When a person dies without a will, there are no laws to help unmarried partners get anything. This means that if a person dies without a will (*intestate*), their partner would not get anything from the estate.

Once drafted, the will is binding until invalidated. A will may be invalidated by the person who wrote it in one of three ways:

1. By destroying it, with the intent to revoke it.
2. By drafting a new will that replaces and invalidates the old will.
3. By marriage or re-marriage, unless a person deliberately states that their will was drafted in consideration of the marriage.

Outside of one of these three circumstances, the will remains valid for an unlimited period of time.

Differences Between a Living Will and a Will/Testament

A living will is a legal document that goes into effect if a person becomes so ill or injured that they are unable to make responsible health-care decisions. A living will is certainly different from a last will and testament, but it does indeed express the will (wish) of the person writing it when they can no longer speak. It’s called a living will because the person is still alive when the will goes into effect. A living will is recognized in most states. If a person does not live in one of the states that recognize living wills, there are other options to decide the type of medical care they will receive. Other advance directives are available, such as a durable power of attorney for health care to appoint a health-care agent or proxy.

A *last will and testament* only takes effect after a person dies, and it is only about who gets belongings such as money or other assets. The person writing the will must choose the person who will execute (carry out the wishes in) the will.

The Importance of a Will

It is important to have a valid will because, without one, a person does not have the power to control who will take over their property after their death. If they die without a will (intestate), their property and possessions (which are called their *estate*) will be divided according to law. This division of property is likely to conflict with how they would like distribute their property.

Writing a will permits a person to clearly name those who will inherit their property and lets their family know that they thought about their needs. They can also say who will be responsible for managing their property. They can name a guardian for any minor children they have, if the children are left without parents.

The will can also be used to state preferences for funeral arrangements, organ donation, or for donating the body to science. Additionally, creating a will provides a person with the chance to reduce the amount of Inheritance Tax that will have to be paid. This is particularly important if they have valuable assets or a highly valued home.

What to Consider When Writing a Will

Think About Who to Name as An Executor. This is the person or persons who will manage the estate after the person's death so that it goes where the person wants it to go. Identifying an executor is even more important if a person's assets (belongings) are considerable. The executor should be someone who is honest and trustworthy. It's good to name a back-up executor, too, in case someone doesn't qualify or can't do the job. A person does not need to finalize who will be the executor, but should at least name two or three potential executors.

Choose a Guardian. If a person has children below age 18, they should appoint someone as a guardian. Usually, their spouse will be the guardian if one parent passes away, but someone else should be named as a substitute guardian in case both parents die together or if the spouse passes away first. Guardians are most often relatives or friends who love and have a relationship with the children.

Identify Beneficiaries. These are people who would benefit from a person's assets. Usually, beneficiaries are family members, relatives, friends, or a charity group. If a person chooses to leave everything to a spouse or one person, then they should name substitute beneficiaries in case the one person is no longer living.

List Assets: Create a list of assets including property, bank accounts, shares, vehicles, jewelry and anything else of value.

Who Gets What: This is where a person decides who will receive their assets. If they intend to give a certain asset to more than one person, it is better to use a percentage rather than a fixed dollar value.

Use the list in Appendix C to create a list of assets and other important information a family may need to know.

Updating a Will

Someone may need to update their will for a number of reasons. Frequent reasons for reviewing and updating a will include:

- ***Changes in the Family, Beneficiaries, or Executors:*** A new baby, a child becomes 18 (or perhaps some significant older age), serious illness or death of a family member, beneficiary, or executor.
- ***Marriage:*** As stated above marriage automatically nullifies a previous will. A new will should be prepared upon marrying.
- ***Divorce:*** A divorce does not invalidate a previous will. But in many states, a former spouse isn't allowed to receive anything from the estate even in they are named. Some don't allow them to be an executor unless it is clearly stated that in the case of divorce they should still be the executor or still receive benefits.
- ***Separation:*** Does not have any effect on a will, so it is best to review and update the will shortly after the spouses separate.
- ***Changes in Financial Circumstances:*** A person's will should be updated if they acquire assets which they would like to leave to certain people. It should be updated if the value or size of their assets becomes too small to provide the amounts of money or property listed in their will.
- ***Changes in Taxes:*** Changes in the tax rates, new taxes or reliefs may prompt a review of someone's will if their estate is large enough to be taxed.
- ***Going to Live Abroad, or Even to a Different State:*** If a person is planning to live in another country a will should be made in that country in order to make it simpler to manage the estate. Even moving to a different state can affect your will.

After a last will and testament is completed, the original must be safely stored. It can be in a file or fireproof lockbox at home, where it can be found by a trusted person. Some people keep their will in a safe deposit box, but remember that someone has to be able to get into the box after a person passes away. Some people solve this problem by having a trusted person listed with them to have access to the safe deposit box.

When a will is reviewed, remember the other accounts and policies where one person gets money when another one dies, no matter what the will says. It’s important to look at anything where a person names a beneficiary, such as:

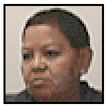
- Life insurance policies
- Retirement accounts such as IRAs and 401(k)s
- Bank accounts that pay when a person dies
- Brokerage accounts that transfer on a person’s death

Activity

It is recommended that you review and update your will each year, so that it is accurate and up to date. To help you get started, complete the checklist below of what you will need to prepare a will. Check the items that you know or have and those you need to research or find.

Preparing to Write a Will	**On Hand**	**Needed**
Full names, addresses and birth dates of your spouse, children and all other beneficiaries.		
Full names, addresses and phone numbers of potential representatives/executors.		
Full name, address and phone number of who you want to have guardianship of your children.		
Location, account numbers, legal signatory, and balances for all bank accounts and financial assets.		
List of retirement accounts including beneficiaries' names and current balances.		
List of insurance policies including company, policy number, and beneficiary.		
Estimated value of items you own like house, real estate, cars, antiques, jewelry, etc.		
List of debts including amount and whom you owe.		
Copies of wills, trusts, divorce settlements, and other important legal agreements or documents.		
A list of special end of life requests including special customs or ceremonies that you would like followed.		

Story of Hope

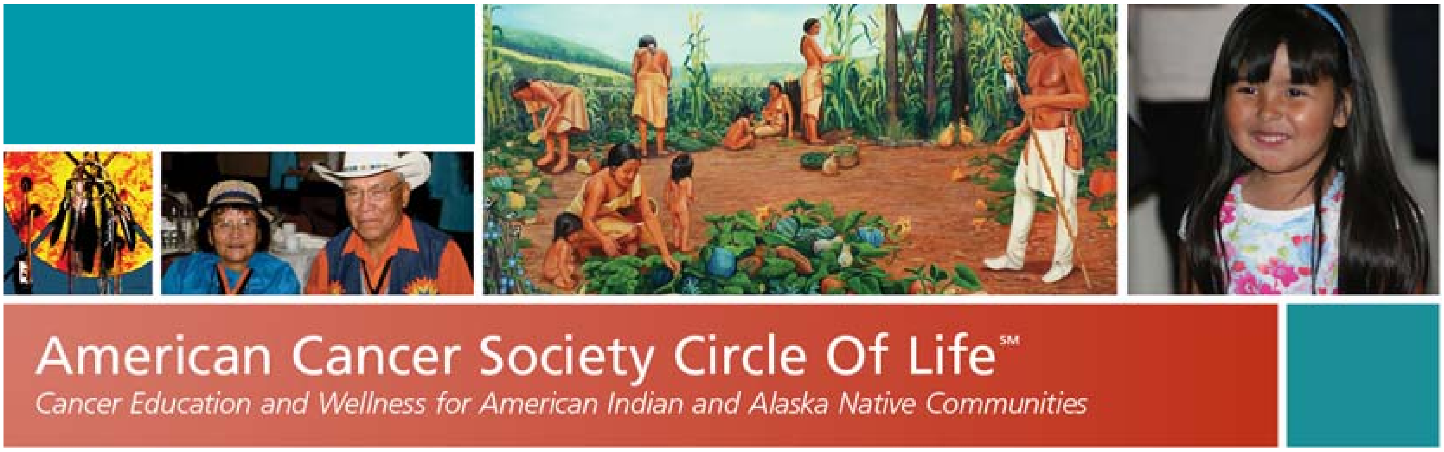


"*My wishes were my stuff that belongs to me how I divided them into three with my three kids and the other thing that was really helpful was thinking about my grandkids and I have a life insurance that I gave onto my grandkids if anything happens. I wrote all this up all my wishes and the house and if something happens to me. So, I did all this because I'm really scared what may happen to me. You know, I've accepted it, if I'm going to go, I'm ready to go. Got all my outfits, what they need to dress me in, got my moccasins made and my shawl, and my crystals that I can take with me. So I prepared, but I'm still scared."* -- Mary Lovato, Santo Domingo Pueblo, Bone and Adult Leukemia Cancer Survivor

(Clark, R., (Producer) & Lovato, M. (Artist). (2007). *Survivor Video Vignettes: Final Will.* [Web]. Retrieved from http://www.natamcancer.org/vignettes/maryl_2.html)

Key Messages

- A person should have a will to protect their loved ones and family. This lets a person say who they want to take care of their children and how they want belongings distributed.
- It is important that a person review their will regularly and update it when needed, especially if their marital or financial status changes.
- Make sure that all legal documents are complete, including a will and an advance directive. Be sure that loved ones know about the advance directive and where to get copies quickly. For a last will and testament, the original must be safely stored where a trusted person can get it.



Wellness along the Cancer Journey:

Nearing the End Of Life

Revised October 2015

Chapter 7: When Death Is Approaching

When Death Is Approaching

Group Discussion			
	True	False	Not Sure
1. There will not be signs that a person is nearing end of life transition.			
2. Are called EMS workers required to revive someone even if they have passed?			

When a person is caring for a loved one who has advanced cancer, they might be there at the time of death. The following covers common events that often happen near the end of life. Knowing more about what to expect may help ease some of the anxiety around events that might otherwise be alarming. This section lists some signs that death may be close.

People often use this time to gather the family to say good-bye to their loved one. They may take turns holding hands, talking, or just sitting quietly. It can also be a time to perform any religious rituals and other activities a person wants before death. It is a chance for many families and friends to express their love and appreciation for a loved one and for each other.

It is important to have a plan for what to do after death, so that people will know what to do during this very emotional time. If the person is in hospice, the hospice nurse and social worker will help. If hospice is not involved, talk with a health care provider about it to know what to do at the time of death. Not all of the following symptoms will happen, but it may be comforting to know about them in case they do. Some of these signs can start days or even a few weeks before a person passes, while others happen just before.

What to Look For

- Profound weakness – usually the person cannot get out of bed and has trouble moving around in bed
- Need help with nearly everything they do

- Less and less interest in food, often with very little food and fluid intake for days
- More drowsiness – may doze or sleep much of the time if the pain is relieved; may be hard to rouse or wake
- A short attention span – may not be able to focus on what is happening
- Confusion about time, place, or people
- Trouble swallowing pills and medicines
- Limited ability to cooperate with caregiver

Possible Changes in Body Function	**What Caregivers Can Do**
• Weakness – has trouble moving around in bed and may become unable to get out of bed • Cannot change positions without help • Trouble swallowing food, medicines, or even liquids • Sudden movement of any muscle, jerking of hands, arms, legs, or face	• Help someone turn and change positions every hour or two. • Avoid sudden noises or movements to lessen the startle reflex. • Speak in a calm, quiet voice to reduce chances of startling the person. • If having trouble swallowing pain medicines, ask the health care provider or hospice nurse about getting liquid pain medicines or a pain patch. • If having trouble swallowing, avoid solid foods. Give ice chips or sips of liquid through a straw. • Do not push to drink fluids. Near the end of life, some dehydration is normal and is more comfortable.

	• Apply cool, moist cloths to the person's head, face, and body for comfort.
Possible Changes in Consciousness • More sleeping during the day • Hard to wake or rouse from sleep • Confusion about time, place, or people • Restless – may pick or pull at bed linens • May talk about things unrelated to the events or people present • May be more anxious, restless, fearful, and lonely at night • After a period of sleepiness and confusion, may have a short time when they are mentally clear before going back into semi-consciousness	**What Caregivers Can Do** • Plan on being there when they are most alert or during the night when a presence may be comforting. • When talking, remind the person who is there and what day and time it is. • Continue pain medicines up to the end of life as prescribed. Usually pain medicines are given around the clock for cancer pain. • If they are very restless, try to find out if they are having pain that isn't controlled by the regular pain medicine. If it appears so, give extra medicines as prescribed for "breakthrough pain," or check with the health care provider or hospice nurse if none is prescribed. • When talking with a confused person, use calm, confident, gentle tones to reduce the chances of startling or frightening them.

	• Gentle touching, caressing, holding, and rocking are usually helpful and comforting.

Possible Changes in Metabolism	**What Caregivers Can Do**
• Less interest in food (The person has less need for food and drink.) • Mouth may dry out. • May no longer need some of their medicines, such as vitamins, chemo, replacement hormones, blood pressure medicines, and diuretics, unless they help make the person more comfortable.	• Apply lubricant or petroleum jelly (such as Vaseline®) to the lips to prevent drying. • Offer ice chips from a spoon, or sips of water or juice from a straw. These may be enough. • Check with the health care provider to see which medicines may be stopped. Medicines for pain, nausea, fever, seizures, or anxiety should be continued to keep the person comfortable.
Possible Changes in Secretions	**What Caregivers Can Do**
• Mucus in the mouth may collect in the back of the throat. (This can cause a very distressing rattling sound, but it usually isn't uncomfortable to the person.) • Mucus may thicken due to a lower fluid intake and build up because the person cannot cough.	• Help make mucus thinner by adding humidity to the room with a cool mist humidifier. • If the person can swallow, ice chips or sips of liquid through a straw may thin the mucus. • Change the person's position. Turning the person to the side may help mucus drain from the mouth. Continue to clean the person's teeth with a soft toothbrush or foam mouth swabs.

	• Certain medicines may help – ask a hospice or home health care provider.
Possible Changes in Circulation and Temperature • Arms and legs may feel cool to the touch as circulation slows down. • Skin of arms, legs, hands, and feet may darken in color and look blue or mottled (blotchy). • Other areas of the body may become either darker or paler. • Skin may feel cold and either dry or damp. • Heart rate may become fast, faint, or irregular. • Blood pressure may get lower and hard to hear.	**What Caregivers Can Do** • Keep them warm with blankets or light bed coverings. • Do not use electric blankets, heating pads, etc.
Possible Changes in Senses and Perception • Vision may become blurry or dim. • They may not hear quite as well, but most people are able to hear even after they can no longer speak.	**What Caregivers Can Do** • Leave indirect lights on as vision decreases. • Never assume the person cannot hear what is being said. • Continue to speak with and touch the person to let them know someone is there. Words of affection and support are likely to be understood and appreciated.

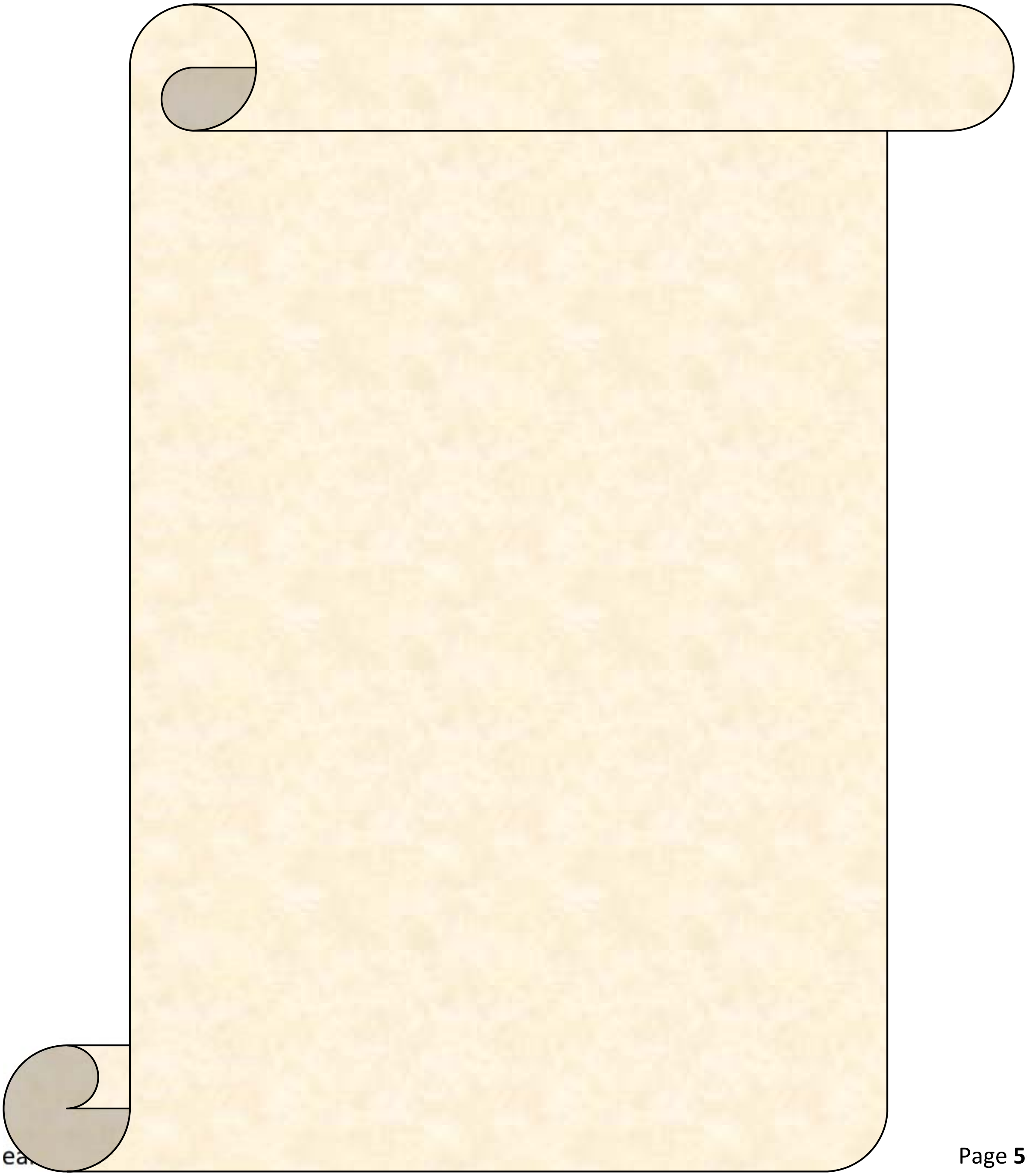
Possible Changes in Breathing	**What Caregivers Can Do**
• Breathing may speed up and slow down due to less blood circulation and build-up of waste products in the body. • Mucus in the back of the throat may cause rattling or gurgling with each breath. • The person may not breathe for periods of 10 to 30 seconds.	• Put the person on their back, or slightly to one side. • Raising the person's head may give some relief. • Use pillows to prop up the person's head and chest at an angle, or raise the head of a hospital bed. • Any position that seems to make breathing easier is OK, including sitting up with good support. A small person may be more comfortable in someone's arms.
Possible Changes in Elimination	**What Caregivers Can Do**
• Smaller amounts of urine, which may be darker in color • When death is near, loss of control of urine and stool	• Put soft waterproof pads under the person's bottom to make it easier to clean up. • If the person has a catheter to take urine out of the body, the home health care provider will teach the caregiver about it.

Signs that Death Has Occurred	**What Caregivers Can Do**
• Breathing stops. • Blood pressure cannot be heard. • Pulse stops. • Eyes stop moving and may stay open. • Pupils of the eyes stay large, even in bright light. • Control of bowels or bladder is lost as the muscles relax.	• After death occurs, it's OK to sit with a loved one for a while. There is no rush to get anything done right away. Many families find this is an important time to pray or talk together and reaffirm their love for each other as well as for the person who has passed away. • If the person dies in the home, caregivers are responsible for calling the proper people. Regulations or laws about who must be notified and how the body should be moved differ from one community to another. A health care provider can get this information. • If a hospice or home care agency is involved, call them first. If funeral arrangements are already made, calling the funeral director and health care provider are usually all that is needed.

If someone calls 911 or emergency medical services (EMS), even after an expected death at home, the law often requires that the EMS team try to revive the person or take them to a hospital. This can complicate the situation and delay funeral plans. Be sure that family and friends are ready and know exactly whom to call, so that they don't dial 911 in confusion or panic.

Activity

Take a few minutes and write down two to three questions that you would want to ask a terminally ill person about any topic: their life, words of wisdom, stories that they want to pass on, etc.



Story of Hope

"At the end I couldn't figure out what I had to do to help my mom die. That last day, my sister Judy and I with the hospice person came, and we gave her a bath. We washed her; we put baby powder on he;r we gave her lotion on her body and rubbed her skin down and combed her hair and were drying her hair. After we finished cleaning her within about a minute or so later, she left us. And it was kind of a peaceful leaving because she wasn't hurting anymore; her death rattle was gone. The medicine lady told us to get away from her feet. Because when spirit leaves the spirit leaves from your feet, and so we had to get away from her feet. She also told us to open the doors, open the windows to the house so when she is leaving us her spirit could go, and so we did that we opened all the doors and everything.

"My sister Judy was really having a hard time; she was crying real hard. She was outside with one of the medicine ladies. She was crying and the lady was trying to help he; they looked up and they saw an eagle that was flying around, flying around, flying around, and the medicine lady said, 'See? There she goes; the eagles are taking her now. Don't cry.' "

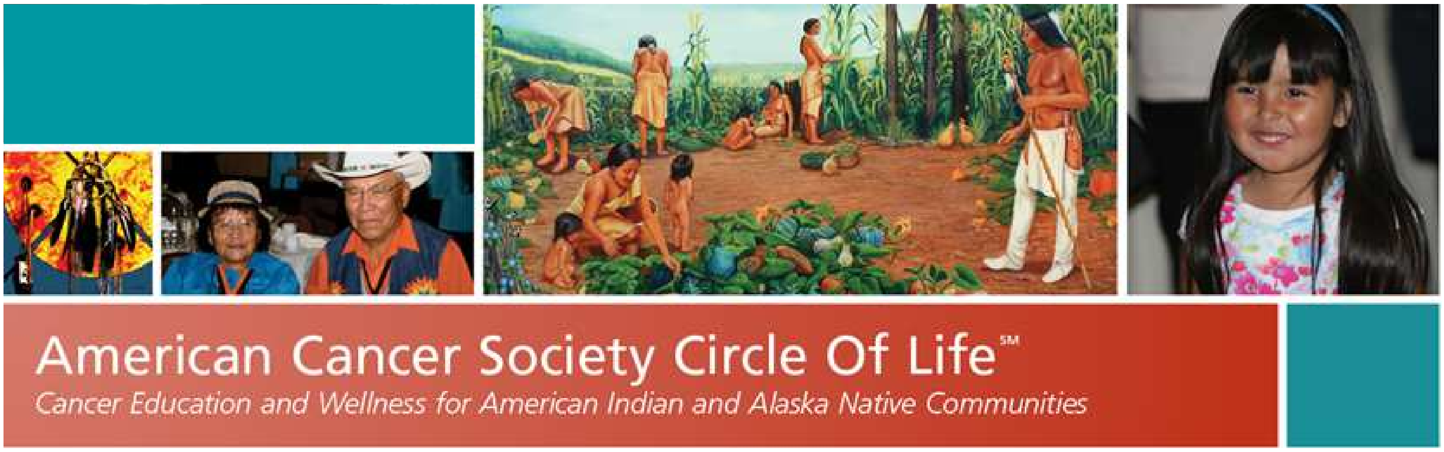
– CeCe Whitewolf, Confederated Tribes of Umatilla Breast Cancer Survivor

(Clark, R., (Producer) & Whitewolf, C. (Artist). (2007). *Survivor Video Vignettes: Mother Dying.* [Web]. Retrieved from http://www.natamcancer.org/vignettes/cc9-palliative.html)

Key Messages

- Take time to talk to the terminally ill person to receive any life lessons or stories they may want to pass on.
- Caregivers are very important. Caregivers are a critical part of a person's support and care team.
- Share caregiving tasks with family and friends. Don't try to do it all.

(Mayo Clinic Staff.(2009). Cancer survivors: managing your emotions after cancer treatment. Retrieved September 24, 2009, from http://www.mayoclinic.com/health/cancer-survivor/CA00071.)



Wellness along the Cancer Journey:

Nearing the End Of Life

Revised October 2015

Chapter 8: Coping with the Death of a Loved One

Coping with the Death of a Loved One

Group Discussion			
	True	False	Not Sure
1. There is only one phase of grief.			
2. There are many emotions that occur during the phases of grief.			

When a person loses someone important to them, they go through a normal process called grieving. Grieving is natural and should be expected. Over time, it can allow the person to accept and understand their loss.

Bereavement is what a person goes through when someone close to them dies. It is the state of having suffered a loss. The person who has lost someone is said to be bereaved.

Mourning is the outward expression of loss and grief. Mourning includes rituals and other actions that are specific to each person's culture, personality, and religion. Bereavement and mourning are both part of the grieving process.

Grieving involves feeling many different emotions over time, all of which help the person come to terms with the loss of a loved one. But keep in mind that grief doesn't look the same for everyone. And, every loss is different.

Grief is a process

Many people think of grief as a single instance or very short period of pain or sadness in response to a loss – like the tears shed at a loved one's funeral. But grieving is the entire emotional process of coping with a loss, and can last a long time. Normal grieving allows us to let a loved one go and keep on living in a healthy way.

Grieving is painful, but it is important that those who have suffered a loss be allowed to express their grief, and that they be supported throughout the process. Each person will grieve for a loved one in a different way. The length and intensity of the emotions people go through will also vary from person to person.

Although grief is described as happening in phases or stages, it doesn't often feel like that to the bereaved person. It may feel more like a roller coaster, with ups and downs that make it hard to see that any progress is being made in dealing with the loss. It is normal for people to feel better for a while, only to become sad again. Sometimes, people wonder how long the grieving process will last for them, and when they can expect some relief. There is no one answer to this question, but some of the factors that affect the intensity and length of grieving are:

- The kind of relationship the person had with the one who died
- The circumstances of the death
- The grieving person's own life experiences

Researchers have studied emotional states that people may go through while grieving. The first feelings usually include shock or numbness. Then, as the person sees how their life is affected by the loss, emotions start to surface. The early disbelief is often replaced by emotional upheaval, which can involve anger, loneliness, disbelief, or denial. These feelings can come and go over a long period of time. The final phase of grief is the one in which people find ways to come to terms with and accept the loss.

Shock, Numbness, and Disbelief

Often, a person's first reaction to a loss is one of shock, disbelief, and numbness. This can last anywhere from a few hours to days or weeks. During this time, the bereaved person may feel emotionally "shut off" from the world. Still, the numbness may be disturbed by pangs of distress, which are often triggered by reminders of the deceased. The person may feel agitated or weak, cry, engage in aimless activities, or be preoccupied with thoughts or images of the person they lost.

The rituals of mourning – receiving friends, preparing for the funeral, and burial – often structure this time for people. They are seldom left alone. Sometimes the sense of numbness lasts through these activities, leaving the person feeling as though they are just “going through the motions” of these rituals.

Painful Emotions Come when Facing the Loss

At some point the reality of the loss starts to sink in, and the numbness wears off. This is sometimes called confrontation – when the feelings of loss are most intense and painful. This is the time that the person starts to face the loss and starts to cope with the changes this loss has caused in their life.

People have many different ways of dealing with loss, so there may be many different, equally intense emotions. During this time, grief tends to come in waves of distress. The person may seem disorganized. They may have trouble thinking and remembering, and doing day-to-day activities. This can last for weeks to months. Some or all of the following may be seen in a person who is grieving – the person may:

- Withdraw socially
- Have trouble thinking and concentrating
- Become restless and anxious at times
- Not feel like eating
- Look sad
- Feel depressed
- Dream of the deceased (or even have hallucinations or “visions” in which the person briefly hears or sees the deceased)
- Lose weight
- Have trouble sleeping
- Feel tired or weak
- Become preoccupied with death or events surrounding death
- Search for reasons for the loss (sometimes with results that make no sense to others)
- Dwell on mistakes, real or imagined, that they made with the deceased

- Feel somehow guilty for the loss
- Feel all alone and distant from others
- Express anger or envy at seeing others with their loved ones

It is often during this time that a grieving person needs the most emotional support. Finding support can be the key to a person's eventual recovery and acceptance of the loss. Family members, friends, support groups, community organizations, or mental health professionals (therapists or counselors) can all help during this time.

Accepting the Loss and Learning to Live without the Loved One

By this time, people have begun to recognize what the loss means to them in day-to-day life. They have felt the pain of grief. Usually, the person comes to accept the loss slowly over the months that follow it. This acceptance includes adjusting to daily life without the deceased.

Like the earlier parts of the process, acceptance does not happen overnight. It's common for it to take as long as a year or more for someone to resolve the emotional and life changes that come with the death of a loved one. The pain may become less intense, but it is normal to feel emotionally involved with the deceased for many years after their death. In time, the person should be able to reclaim the emotional energy that was invested in the relationship with the deceased, and use it in other relationships.

Grieving Can Go on for Many Years

Adjusting to the loss does not mean that all the pain is over for those who were very close to the deceased. Grieving for a loved one includes losing the future someone expected with that person. This must also be mourned. The sense of loss can last for decades. For example, years after a parent dies, the bereaved may be reminded of the parent's absence at an event they would have been expected to attend. This can bring back strong emotions, and may call for mourning yet another part of the loss.

Grief Can Take Unexpected Forms

Emotions are different when the relationship was difficult. A person who had a difficult relationship with the deceased (a parent who was abusive, estranged, or abandoned the family, for example) is often surprised after their death because the emotions are so painful. It's not uncommon to have profound distress as the bereaved mourns the relationship they had wished for with the person who died, and lets go of any chance of achieving it. Others might feel relief, while some wonder why they feel nothing at all on the death of such a person. Regret and guilt are common, too. This is all part of the process of adjusting and letting go.

Grief Can Be Different If the Loss Comes after a Long Illness

The grief experience may be different when the loss occurs after a long illness rather than suddenly. When someone is terminally ill, their loved ones often start to grieve before the death because they know that the loss is going to happen. This is called "anticipatory grief," and it is a normal response. It can help people complete unfinished business and prepare the person for the actual loss, but it might not lessen the pain they feel when the person dies.

Usually, the period just before the person's death is a time of physical and emotional preparation for those close to them. At this stage, loved ones may feel the urge to withdraw emotionally from the person who is ill.

Many people think they are prepared for the loss because death is expected. But when their loved one actually dies, it can still be a shock and bring about unexpected feelings of sadness and loss. For most people, the actual death starts the normal grieving process.

Major Depression and Complicated Grief

It is common for people to have sadness, pain, anger, bouts of crying, and a depressed mood after a loved one dies. It is important to know about the normal grief responses and when the situation might be worsening into clinical depression.

About one in five bereaved people will develop major depression (also called clinical depression). This can often be helped by therapy and medicines. People at highest risk for clinical depression include those who have been depressed before, those with no support system, those who have had problems with alcohol or drug abuse, or those who have other major life stresses.

Symptoms of major depression not explained by normal bereavement may include:

- Constant thoughts of being worthless or hopeless
- Ongoing thoughts of death or suicide (other than thoughts that they would be better off dead or should have died with their loved one)
- Being unable to perform day-to-day activities
- Intense guilt over things done or not done at the time of the loved one's death
- Delusions (beliefs that are not true)
- Hallucinations – hearing voices or seeing things that are not there), except for "visions" in which the person briefly hears or sees the deceased
- Slower body responses and reactions
- Extreme weight loss

If symptoms such as these last for more than two months after the loss, the bereaved person may benefit from getting professional help. If the person tries to hurt themselves, or plans to do so, they need help right away.

In some people, the grieving process can go on for a long time. This happens more commonly in those who were very close to the deceased. It is most often caused by attempts to deny or get away from the pain or to avoid letting go.

If normal mourning does not occur, or if the mourning goes on for a long time without any progress, it is called "complicated grief" or "unresolved grief." Symptoms of this might include:

- Continued disbelief in the death of the loved one, or emotional numbness over the loss
- Being unable to accept the death

- Feeling preoccupied with the loved one or how they died
- Intense sorrow and emotional pain, sometimes including bitterness or anger
- Being unable to enjoy good memories about the loved one
- Blaming oneself for the death
- Wishing to die to be with the loved one
- Excessively avoiding reminders of their loss
- Continuous yearning and longing for the deceased
- Feeling alone, detached from others, or distrustful of others since the death
- Trouble pursuing interests or planning for the future after the death of the loved one
- Feeling that life is meaningless or empty without the loved one
- Loss of identity or purpose in life, feeling like part of themselves died with the loved one

For some people who are taking care of a loved one with a long-term illness, complicated grief can actually start while their loved one is still alive. Caregivers under severe stress, especially if the outlook is bleak, may be at higher risk of having abnormal grief even before the death.

If someone has any of the above symptoms of major depression or complicated grief, discuss it with a qualified health or mental health professional. Treatment is important, since people with complicated grief are at risk of their emotional illness getting worse, and are at higher risk of committing suicide.

Coping with Loss

Ideally, the bereaved person will work through the process of grieving. With time and support, they will accept and make sense of the loss, experience the pain, and adapt to a new life and identity.

If someone has lost a loved one, the following suggestions may help them cope with the loss:

- Feel the pain and all the other emotions, too. It does not work for a person to tell themselves how to feel or let others tell them how they should feel.
- Be patient with the process. A person should not feel pressure from their own or others' expectations. Accept that each person needs to experience their pain, their emotions, and their own way of healing – all in their own time. Don't judge a person's emotions or compare them to others. No one can tell a person how they should mourn or when to stop.
- A person needs to be able to recognize their feelings and cry when needed. This is needed for healing.
- Get support. A person needs to talk about their loss, their memories, and their experience of the life and death of a loved one. Some people think they are protecting their family and friends by not expressing their sadness. They should remember that they can ask others for what they need. For instance, they can find and talk to others who have lost a loved one.
- Try to maintain a normal lifestyle. A person should avoid major life changes (for example, moving, changing jobs, changing important relationships) within the first year of bereavement. This helps allow a person to keep their roots and some sense of security.
- They should take care of themselves, for example, by eating well and exercising. Physical activity helps to release tension. They can also allow themselves small physical pleasures, like warm baths, naps, and favorite foods, to help renew themselves.
- They should avoid drinking too much alcohol or using other drugs. This can harm the body as well as dull the emotions. It is likely to slow recovery and may cause new problems.

- A person will need to forgive themselves for all the things they said or didn't say or do. Compassion and forgiveness for oneself and others are important in healing.
- Take a break from grief. Although everyone must work through grief, people do not need to focus on it all the time. It is healthy to find distractions like going to a movie, dinner, or a ball game; reading a good book; listening to music; or getting a massage or manicure.
- Prepare for holidays and anniversaries knowing that strong feelings may come back. Decide whether to keep certain family traditions or create new ones. Plan in advance how to spend time and with whom. Do something to honor the memory of the loved one.
- Join a bereavement support group. Other people can encourage, guide, and offer comfort. They can also offer practical ideas and information, and help a person feel less alone. If there is not a nearby support group, online groups may be helpful.
- When a person feels ready, they can do something creative. Some options include:
    - Write a letter to the person who died.
    - Start keeping a journal.
    - Make a scrapbook.
    - Paint pictures.
    - Plant flowers or trees.
    - Become involved in a cause or activity that the deceased person loved.

Appendix E has some other ideas for coping with the loss of a loved one. It may be helpful to copy this page and put it somewhere to review it from time to time.

Family Changes

When a loved one dies, it affects all their family members and loved ones. Each family finds its own ways of coping with death. A family's attitudes and reactions are shaped by cultural and spiritual values, as well as by the relationships among family members. It will take time for a bereaved family to regain its balance.

The ability of each member to grieve with one another is important in helping the family cope. Each person will experience the loss differently and have different needs. As hard as it may be, it is important for family members to remain open and honest when talking with each other. This is not the time for family members to hide their emotions to try and protect one another.

The loss of one person in a family means that roles in the family will change. Family members will need to talk about the effects of this change and the shift in responsibilities. This time of change is stressful for everyone. It is important to be even more gentle and patient with each other.

Getting Professional Help for the Grieving Process

Bereavement counseling is a special type of professional help. A person may be able to find it through hospice services or from a health care provider. This type of counseling has been shown to reduce the level of distress that mourners go through after the death of their loved one. It can help them move more easily through their grief. Bereavement counseling can also help them adjust to their new lives without the deceased.

Helping Someone Who Is Grieving

It is common to feel awkward when trying to comfort someone who is grieving. Many people do not know what to say or do. Use the following suggestions as a guide.

What to Say

- Acknowledge the situation. Example: “I heard that your_____ died.” Use the word “died.” This shows a person is more open to talk about how the other person really feels.
- Express concern. Example: “I’m sorry to hear that this happened to you.”
- Communicate genuinely and don’t hide feelings. Example: “I”m not sure what to say, but I want you to know I care.”

- Offer support. Example: “Tell me what I can do for you.”
- Ask how the bereaved person feels. Don’t assume how they will feel on any given day.

What to Do

- Be there. Even if a person does not know what to say, just having someone near can be very comforting.
- Listen and give support. But don’t try to force someone if they are not ready to talk.
- Be a good listener. Accept whatever feelings the person expresses. Even if you can’t imagine feeling like they do, never tell them how they should or shouldn’t feel.
- Give reassurance without minimizing the loss. Try to have empathy with the person without assuming to know how they feel.
- Offer to help with errands, shopping, housework, cooking, driving, or yard work. Sometimes people want help and sometimes they don’t. Even if they don’t accept the offer of help, they’re not rejecting a person or their friendship.
- Avoid telling the person “You’re so strong.” This puts pressure on the person to hold in feelings and keep acting “strong.”
- Continue to offer support even after the first shock wears off. Recovery takes a long time.
- It may help to check in with the bereaved on anniversaries of the death, marriage, and birthday of the deceased, since those can be especially difficult.

If a grieving person begins to abuse alcohol or drugs, neglects personal hygiene, develops physical problems, or talks about suicide, it may be a sign of complicated grief or depression. Someone close to them will want to suggest they think about getting professional help.

If there are signs they may be thinking about suicide, do not leave them alone. Try to get the person to get help from their health care provider or the nearest hospital emergency room right away. If that is not possible, call 911. If it is safe to do so, remove firearms and other tools for suicide.

Grief during Childhood

It is a very common myth that children cannot understand death. How old a child is at the time of the death is important because a child's understanding of death changes with age. Preschool children usually think death is short term and reversible. Between the ages of 5 and 9, they understand that the person is gone, but see it more as a separation. After about ages 9 or 10, they begin to understand that death is final.

Children grieve. They just don't have all the ways to cope that adults do. They often have feelings like sadness, anger, guilt, insecurity, and anxiety, even though they might need help naming these feelings. Children sometimes show anger toward surviving family members. They may start having behavior or discipline problems. They may think the death is their fault, especially if they had once "wished" the person dead or were ever angry at the person. Or they may start having nightmares or acting younger than their age. Sometimes they may seem unaffected by the loss and then express their feelings about the death at unexpected moments.

Talking with Children about Death

It's hard to comfort others when a person is deep in their own grief. Parents may not want to discuss death with their children because they don't want to upset them. Or they may not want to worsen their own pain. But talking with them about death will help the children deal with their fears.

Children's responses to death are often very different from those of adults. Sometimes a child's feelings or questions about death may seem inappropriate or upsetting. But it is important to recognize that they are also trying to understand and accept what has happened. A parent can help them by listening and showing interest in what they have to say.

Answer whatever questions they may have as openly and honestly as possible. Telling children that someone “went away” or is “sleeping”can lead to confusion and fear. If a small child knows that sickness caused the death, it is important to explain that only serious sicknesses cause death. With small children, it may be helpful to talk about dead flowers, insects, or birds, as a way to explain death.

A parent may want to use the following suggestions when talking to a child about death:

- Explain what happened in a way they can understand. Children know when a person is hiding something, so be open and honest.
- Assure the child that this is not their fault; they didn’t cause the death.
- Encourage them to talk. Listen and accept their feelings no matter how hard it may be.
- Answer their questions in brief and simple terms. Telling them they are too young to understand only avoids dealing with the problem and may upset them even more. It is OK to not have all the answers.
- Reassure them that they will still be loved and taken care of. Tell them where they can expect to live and who will be taking care of them if they have lost a parent.
- Show affection, support, and consistency. Let the child know that someone will be there to help as much as possible. Be sure they have people in their lives they can count on.
- Share feelings using words they will understand and in a way that won’t be overwhelming. For example, it is OK to let the child know the parent is hurting, too. If a parent tries to hide their feelings, the child may think they shouldn’t share theirs.

Years ago, people believed that children should not be included in funerals, because it would be too hard for them, they were too young to understand, or they would be frightened by other people’s distress. Since then, it has been learned that this is not true. Children have later said they often felt betrayed when they could not say good-bye to someone they loved. They felt that their relationship with the person who died was not valued; that death was not a natural part of life, but instead something too frightening to confront; and that they were emotionally not able to cope.

Attending the funeral helps children understand that death is final. Explain to them that a funeral is the way we say good-bye to the people we love. Depending on their age, attention span, and how much adult supervision they need, children may take part in all of the ritual or only some of it.

If children will be at the funeral, they should be prepared for what they will see and hear. Someone should take them aside and tell them enough detail so they will know what to expect. If there will be a viewing with an open casket, the child needs to know that. Depending on how young they are, it might be useful to talk about what it means to be dead. Explain that people will come to the funeral home to visit with the family and offer their sympathy. Also explain any other routines or rituals that will be followed. If there is a religious service, describe what will happen there. Tell them if there will be a trip to a cemetery where the casket will be placed in the ground and covered up. They should know that they may see people cry, and that it is OK. They will see the normal expressions of how people feel when they lose someone important to them. Seeing this gives the child permission to express their emotions.

Whatever social ritual may happen afterward should also be explained. Children sometimes have a hard time understanding what looks like a party after services where people looked pretty sad. Explain that people can’t be sad all the time and there will be other times when the sadness will come back. Children also should expect that the sadness we feel when someone has died can last a while, but eases as time goes on.

Children will generally want to take part in this ritual with their family. If they seem frightened by what they imagine a funeral to be, they probably have a false impression or misunderstanding about it. It is a rare child who does not want to take part in something that the whole family is doing, but if they don’t, gently ask the child what they think will happen and what they are worried about. For example, the child may not fully understand the transition from life to death and worry that the person is still alive when they are put into the ground. Remind them again what being dead means and that the person as they knew them is no longer here.

Losing a Child

Facing the death of a child is likely the hardest thing a parent ever has to do. People who have lost a child have stronger grief reactions. They often have more anger, guilt, physical symptoms, greater depression, and a loss of meaning and purpose in life. A loss is tragic at any age, but the sense of unfairness of a life unfulfilled magnifies the anger and rage felt by parents.

A longer and slower bereavement and recovery should be expected when someone loses a child. The grief may get worse with time, as the parents see others going through the milestones they expected to pass with their child.

Bereaved parents may especially be helped by a grief support group. A group may be available in the local community. A parent can ask their child's cancer care team for referral to counseling or local groups.

They can also contact Compassionate Friends, a nationwide self-help organization offering support to families who have experienced the death of a child, of any age, from any cause. It publishes a newsletter and other materials on parent and sibling bereavement. Compassionate Friends also refers people to nearly 600 local chapters. Online support groups, such as those at GriefNet, can be another way to connect with others.

Activity

Spotting depression as soon as possible can stop a downward spiral of sadness and inability to function. Many successful ways of treating depression are now available to help people regain joy, hope, and the ability to cope.

Below are some of the signs and symptoms of depression.

Symptom	**Yes**	**No**
You feel sad or ”empty“ almost every day for most of the day.		
Your days bring little or no pleasure.		
You are either too restless or slowed down most of the time.		
You have trouble making decisions or have problems concentrating.		
You have lost interest in eating, or you are overeating. You have gained or lost weight without dieting.		
You have trouble sleeping, wake up early, or find yourself oversleeping.		
You feel many aches and pains that don’t go away.		
You have lost interest in sex.		
You cry often.		
You feel tired or a lack of energy almost every day.		
You have thought about hurting yourself or attempted suicide.		

It isn’t unusual for caregivers to have a couple of these symptoms for a short time. However, they may mean that they are at risk for becoming depressed.

If someone has symptoms that last for two weeks or longer, or their symptoms are severe enough to interfere with normal day-to-day life, see a health care provider or mental health professional to be checked for depression. It may be helpful to print this checklist and take it to show a health care provider or health care team.

Looking at the last question, if you or someone you know longs to die, they may be seriously depressed. See a health care provider right away.

Story of Hope

"Indian people generally, don't deal well with death. We don't take lightly losing someone that we love. We hold that death with us for a long time. When it comes to the point of examining your own mortality, that's a real difficult task. Because then you have to ask yourself questions of I don't want to deal with not being here. I love life. That's where I am at. I can't imagine not being here. But there's no guarantee that, you know, tomorrow I won't be here because of some other intervening cause that I have no control over. But right now, you know, Creator knows that I am not ready. He knows all the reasons, but whether or not that's within my control, I don't know. So examining mortality, I think is a real healthy thing to do for Indian people and for cancer survivors, in particular. I know that a lot of people that are Indian that have cancer and that have survived have a real difficult time finding other people to talk to about mortality. And we need to do that. We need to slay the dragon. Because if we are really being true to our cultural beliefs and our spirituality, then there's no fear. Because we are being taken care of. It doesn't matter."

– Bonnie "Heavy Runner" Craig, Blackfeet Ovarian Cancer Survivor

(Clark, R., (Producer) & Craig, B. (Artist). (2007). *Survivor Video Vignettes: Perceptions of Death.* [Web]. Retrieved from http://www.natamcancer.org/vignettes/bc2-palliative.html)

Key Messages

- After the death of a loved one, family and friends need to take care of themselves, allow themselves to feel their emotions, be in touch with supportive friends and family, and focus on staying healthy.
- If someone keeps having sadness and anger, they should talk to a health care provider. Many times these feelings will fade, but other times they develop into depression, which can be treated.
- After the death of a loved one, family and friends are normally able to ease back into a new daily routine over time. It may take time to gain back energy and strength.

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities

American Cancer Society Circle Of Life℠

Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness along the Cancer Journey:

Nearing the End Of Life

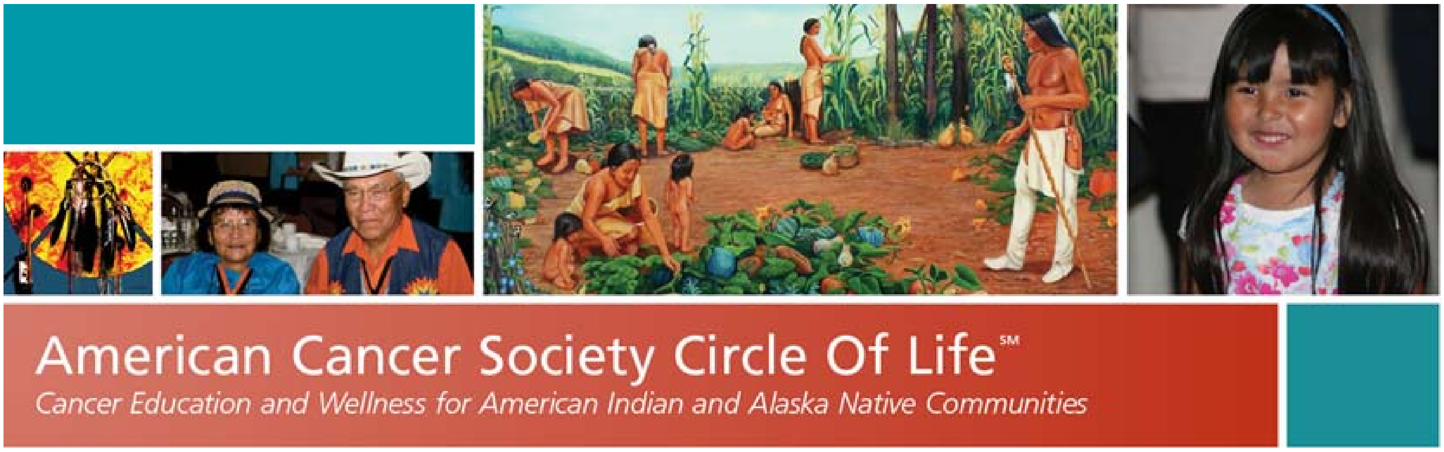
Revised October 2015

Chapter 9: Knowledge Questions

Knowledge Questions

Nearing the End of Life Knowledge Questions	True	False	Not Sure
1. Health care providers cannot assess advanced cancer.			
2. Cancer that is considered to not to be curable may be called advanced cancer.			
3. Those being treated for cancer don’t have the right to make decisions about the care they receive.			
4. Care at the end of life focuses on quality of life.			
5. There are many emotions that occur when someone is approaching the end of life.			
6. There is no difference between palliative care and hospice care.			
7. Palliative care begins at diagnosis and continues during cancer treatment and beyond.			
8. Hospice care begins one year prior to the end of life.			
9. A person’s health care wishes can be honored through legal means.			
10. Advance directives require patients to have treatment.			

Nearing the End of Life Knowledge Questions	True	False	Not Sure
11. There is only one type of advance directive.			
12. A will needs to be updated every year.			
13. Birth of children and other life events are important when reviewing a will.			
14. There will not be signs that a person is nearing end of life transition.			
15. Are called EMS workers required to revive someone even if they have passed”			
16. There is only one phase of grief.			
17. There are many emotions that occur during the phases of grief.			



Wellness along the Cancer Journey:
Nearing the End Of Life

Revised October 2015

Chapter 10: Appendices

Appendices

Appendix A: Frequently Asked Questions about Advance Directives

Some people have questions about advance directives. This list has key questions that will help a person understand the information they need to help make decisions about their treatment.

What is a terminal condition?

A terminal condition is an irreversible illness that in the near future will result in death. It may also be a state of permanent unconsciousness from which the person is not likely to recover. Examples of terminal conditions include advanced cancers, multiple organ failures, or massive heart attacks and strokes. In many states, a terminal illness is defined as one in which the person will die “shortly” whether or not medical treatment is given. These definitions can complicate or delay the use of a living will.

What is a life-sustaining medical treatment?

In most cases *life-sustaining medical treatment* is a mechanical or artificial means that sustains, restores, or substitutes for a vital body function. Life-sustaining treatment can prolong the dying process for a terminally ill person. States have different definitions, so it is important to check state laws. Life-sustaining medical treatment may include the following:

- Cardiopulmonary resuscitation (CPR)
- Artificial respiration (includes mouth-to-mouth breathing, manual ventilation, or a ventilator or respirator – a machine that pushes air into the lungs)
- Medicines to help with blood pressure and heart function
- Artificial nutrition or hydration (liquid food or fluids given through a tube to the stomach or into a vein)
- Dialysis (a process that does the job the kidneys normally do)
- Certain surgical procedures (such as amputation, feeding tube placement, tumor removal, or organ transplant)

Nutrition and hydration (food and water) are not usually defined as life sustaining unless they are given through a feeding tube or into the vein (IV). Comfort measures, which are medicines or procedures needed to provide comfort or ease pain, are not usually defined as life sustaining. In some states, tube feedings and IV fluids are considered comfort measures.

When should I make an advance health care directive?
The best time to make an advance directive is before one is needed! In other words, before a person becomes too sick to make their own decisions about what medical care they want to take or refuse. Young people as well as older people should think about making an advance directive. Advance directives can be changed or revoked (taken back) at any time. They should be reviewed and updated if a person is found to have a serious illness.

It's very important that loved ones know that a person has written an advance directive and what medical care they want in certain situations. But even the most detailed living will can't possibly describe every medical event that could happen. That's why some people write two advance directives – a medical power of attorney along with a living will or Five Wishes form. But a person can use any kind of advance directive as a starting point to discuss difficult subjects like illness and dying.

That is why a person may want to use an advance directive as a chance to discuss difficult subjects like illness and dying. Through open talks with loved ones, a person can explain what is important to them and what kind of treatments they do and do not want done. This is a good thing to do at any age. It can save loved ones from a lot of guilt, uncertainty, and conflict in the event they must decide about a person's care. A person's loved ones can help make sure that their wishes are followed, but first they must know and understand what the person would want.

What happens when I have an advance health care directive?
If a person cannot make their own medical decisions, these decisions will be made for them. But if they have an advance directive, the decisions will be guided by what the person said they wanted. Decisions will be listed in the living will or made by the person they chose as their agent or proxy (substitute decision maker). It is important to make sure that the family, health care providers, and

others who might be contacted know that a person has an advance directive and what is in it. These people also need to have a copy of the most recent advance directive so that it can be used in medical treatment. It is better to have extra copies so that loved ones can find the directive quickly.

A person should talk to all of their family about their advance directive. They should be sure that their family is clear about who their agent and back-up agent will be, and what a person has told them about their wishes. There may be problems if everyone in the family does not know about or does not support the choices a person has outlined in their advance directive. Arguments, family conflicts, and emotional objections can sometimes lead health care providers and hospitals to the "safest" route of care – aggressive treatment that can prolong death for a long time. This may not what a person would want.

How will my health care provider know that I have an advance health care directive?

If a person has any type of advance directive, they should tell people close to them that they have one and where it is kept. The person should give copies of the advance directive to the proxy or agent (who will make decisions for them), the back-up agent, family members, and friends who would be contacted if they become ill. A person can talk it over with their doctor, but keep in mind that the doctor's office records are not likely to be available to a hospital or facility where the person is admitted.

Do not keep an advance directive locked up where no one can find it or get to it. Have extra copies where they are easy to find. It is up to the person, their agent, or a family member to give a copy of an advance directive to their health care provider and hospital when it's needed.

Federal law requires that hospitals, nursing homes, and other health care agencies ask at the time of admission whether or not a person has an advance directive. If they are unable to answer the question or if the advance directive is not available, it may not be included in their medical record. In that case, the advance directive may not be used to guide care according to the person's wishes.

Does the health care provider have to follow my advance health care directive?

There are some times that a health care provider may reject a medical decision made by someone or their agent based on their advance directive. For instance:

- When the decision goes against the health care provider's conscience
- When the decision is against the health care institution's policy
- if the decision violates accepted health care standards

In such cases, the health care provider or facility must tell the person or the person's agent right away. The person may be transferred to another facility that will honor their decision.

Will my advance health care directive be used if I am taken to an emergency room?

An advance directive is valid in an emergency room only if the health care providers there know about it and have a copy. In serious emergencies, it may not be possible for health care workers to find out that someone has an advance directive before medical care begins. If a loved one calls emergency medical services (911) at a time a person cannot speak for themselves, the advance directive may not be honored. This is another reason why a person's family should know their wishes before such a situation happens.

What happens if I do not have an advance health care directive?

It is estimated that about one in four adults in the United States have advance directives. If a person does not have an advance directive, they may get medical care that they do not want. If there is no advance directive, the health care provider may ask a person's family about their treatment. Some state laws require that the spouse (unless legally separated) must be asked first, followed by adult children, parents, and adult brothers and sisters. But some states do not have laws that require health care providers to check with family members. And it is common for family members (especially those who aren't close to the person) to not know what a person would want. Family members may disagree on certain aspects of a person's care, which may cause delays or them not getting the care they want. For example, It's unlikely that a trusted friend or unmarried partner will be consulted without an advance directive naming that person as an agent or proxy.

In some cases, a court may appoint a legal guardian to make health care decisions if a person does not have an advance directive. This is why it is important for a person to express their wishes in a written advance directive ahead of time. It is also helpful to discuss their wishes with their health care provider, agent, and those close to them.

Do I need a lawyer to write my advance health care directive?

Although a lawyer can be helpful, a person does not need a lawyer to write their advance directive. Some states have forms that a person must use, and each state has certain requirements. Visit caringinfo.org for sample forms and directives that meet each state's requirements.

Can I have an advance health care directive in more than one state?

Most states have their own rules about what they will accept as a valid advance health care directive. Some states accept an out-of-state directive if it meets the legal requirements of the state in which the person wants to use it. Some experts suggest having an advance directive for each state in which a person spends a lot of time. If a person wants to use an advance directive in a state other than that in which they signed it, it is a good idea to check with a lawyer in order to avoid potential problems.

Does having an advance health care directive affect my life insurance?

No. No one, including health insurance companies, can require a person to have or prevent them from having an advance directive. Having an advance directive will not affect any terms of a person’s life insurance.

Does having an advance health care directive affect my health care?

Having an advance directive does not mean someone has given up their right to make any decisions about their care as long as they are able to do so. Having or not having an advance directive will not affect the quality of someone’s care while they can make their own decisions. Treatment and comfort measures are still offered.

The advance directive only takes effect when a person cannot speak for themselves. At that point, certain treatments or cure measures may be withheld if that is what the person requested. Any person who is mentally able can change or revoke (take back) his or her advance health care directive at any time.

Can I have both a living will and a power of attorney for health care?
Yes. A person can have a living will and a durable power of attorney for health care at the same time. In most cases, a person can also provide extra instructions in another type of advance directive for situations not covered by the living will.

If a person has more than one kind of advance directive, be sure that the person named as the agent or proxy in the power of attorney for health care has copies of the living will and any other advance directive. The agent or proxy must clearly understand what you want.

It’s also very important to be sure that these documents don’t conflict with each other, so that there will be no confusion about a person’s wishes if they can’t speak for themrselves.

Some states allow a person to have a single, combined advance directive/living will document. But it is important to check state requirements to find out what the state legally accepts.

Can I change my mind about what is written in my advance health care directive?
Yes. Once a person makes an advance directive, they may change or revoke it (take it back) at any time while they are mentally able to do so. Changes should be signed, dated, and witnessed. A person should tell their proxy or agent, loved ones, and health care provider if they change or cancel their advance directive.

If they are writing a new advance directive, they should destroy all copies of the old advance directive so there is no confusion on the part of their agent or their family. Some states require that a person notify their health care provider in writing when they make changes to their advance directive or write a new one.

Is my advance health care directive valid if I am at home?
Someone who is dying but who is not in a health care facility may face problems in having an advance directive honored in an emergency. Some states have addressed this issue. A few states allow 911 emergency medical services to refrain from trying to revive terminally ill persons who have a “do not resuscitate” order written by a health care provider. As part of this, those states require that people who wish to die at home post a special orange DNAR form or wear a special bracelet labeled “do not resuscitate.” Each state is different. This is something that a person should ask their local health care provider and EMS about.

What is a “do not resuscitate” order?
Do not resuscitate, or DNR, is a medical order written by a health care provider for a person in a hospital. It tells the health care team taking care of a person that CPR is not to be used if their heart or breathing stops. Each time a person who does not want CPR is admitted to a hospital or facility, they should be sure that their health care provider knows CPR is not wanted.

The in-hospital DNR orders do not help people once they go home. Advance directives often include instructions not to start CPR. This may not help in emergencies when no one knows that they have an advance directive. But if family and loved ones know, they may be able to avoid an emergency treatment situation.

What are “end-of-life decisions?”
End-of-life decisions are choices a person can make about how they wish to be treated when they are dying. End-of-life decisions can include whether to accept or refuse treatments that prolong life. An advance directive is one way to let others know about a person’s decisions based on what is important to them. Again, it helps if everyone close to the person fully understands what they want at

this time of their life. This makes it is as easy as possible for loved ones to carry out the person's wishes.

What is "euthanasia?"

The word euthanasia comes from a Greek phrase meaning "a gentle and easy death." It is defined as any action or omission that causes death with the purpose of ending suffering due to illness. This means there are two major types of euthanasia: active and passive.

Active euthanasia is when someone other than the person takes active measures to end their life, such as personally giving a deadly dose of a drug. This is illegal in the United States, even if the person asks for it.

Passive euthanasia is defined as stopping treatment that prolongs life, such as breathing machines or feeding tubes. This allows a terminally ill person to die naturally, and does not further prolong death.

What is assisted suicide?

Assisted suicide is different from active or passive euthanasia. Assisted suicide is giving someone the means to take their own life. For instance, a health care provider may write a prescription for deadly dose of drugs that the person may choose to take when they are ready.

As of mid-2015, only the states of Oregon, Montana, and Washington allow health care providers to prescribe a lethal dose of medicine for terminally ill people who wish to end their lives. Those states' Death with Dignity Acts forbid active euthanasia; that is to say, no one else can give the lethal dose of medicine. The person must do that for themselves. These laws contain many requirements that must be met before a person is given the means to hasten death. (The Montana Supreme Court ruled in 2009 that assisted suicide is not illegal in the state, but there's no specific law that allows it.) Even then, not all health care providers in those states will write such prescriptions even for people who meet all the requirements. Health care providers can refuse to prescribe these drugs based on conscience.

All of these states have laws that prohibit active euthanasia; that means no one else can give the lethal dose of medicine. The patient must do that for themselves.

Appendix B: How to Write an Advance Health Care Directive

A person should learn about advance health care directives in their own state before they begin. A person may wish to look into one or more of the resources listed in this appendix.

- Discuss decisions and wishes with a spouse or partner, family members, close friends, a health care provider, and/or attorney. Telling those close to you about your end-of-life decisions will help ensure that your wishes are carried out.

- Decide what you want, such as a living will, durable power of attorney for health care, and/or other advance health care instructions. Understand the meaning of each and the differences between them.

- Decide who you want as your health care proxy or agent (decision maker). This is one of the most important decisions you will ever make. Choose this person carefully. Pick someone you believe will be able to carry out your wishes even if they include DNR or denying other life-sustaining treatments. Talk with the person to be sure they're OK with doing this for you and that they understand your wishes. And remember it's good to have a second person to act as a backup in case your first choice cannot do it.

- Decide what you want your advance directive to say. If you choose a living will, be specific about such things as CPR, artificial respiration (breathing), medicines to make your heart work, kidney dialysis, artificial feeding (tube or intravenous), and certain surgical procedures.

- If you need help writing an advance directive, contact one of the resources listed below or an attorney. You do not have to use an attorney to write an advance directive. An attorney may know the most about the laws in your state, but only you can make the decisions about your future care.

- Have one or more witnesses sign your advance directive (or whatever is required in your state).

- If you have appointed an agent (durable power of attorney for health care), give a copy of your advance directive to them and ask them to keep it in a safe place where it can be found quickly if needed. Be sure that family members who are likely to be nearby have copies, and that they know who your agent is.

- Keep copies of your advance directive in a handy, easy-to-find place so that someone else can find it if you are in the hospital and need it. Make sure that those close to you know where your advance directive is kept.

- Do not lock an advance directive in a safe-deposit box, home safe, or filing cabinet that only one person can open.

- Be sure the advance directive is clearly marked.

- Every once in a while, talk to your health care agent about your advance directive in order to remind them of this important responsibility. If your wishes change, be sure to talk this over with your agent, your loved ones, and your health care providers.

Appendix C: Personal Affairs Worksheet

You can fill out this worksheet to help your family deal with your personal affairs after you're gone. Be sure to let your loved ones know about this list. Try to keep it up to date and in a safe place. Make sure that only those you trust have access to it.

Banks, savings and loans
Contact information

What needs to be done

Life insurance company
Contact information

What needs to be done

Health insurance company
Contact information

What needs to be done

Disability insurance company
Contact information

What needs to be done

Homeowners' or renters' insurance company
Contact Information

What needs to be done

Burial insurance company
Contact information

What needs to be done

Unions and fraternal organizations

Contact information

What needs to be done

Attorney

Contact information

What needs to be done

Accountant
Contact information

What needs to be done

Executor of the estate
Contact information

What needs to be done

Tax returns and monetary records/Internal Revenue Service

Where are documents located/contact information

What needs to be done

Social Security office

Contact information

What needs to be done

Pension or retirement plans
Contact information

What needs to be done

Department of Veterans Affairs
Contact information

What needs to be done

Investment companies
Contact information

What needs to be done

Mortgage companies
Contact information

What needs to be done

Credit card companies
Contact information

What needs to be done

All other lenders
Contact information

What needs to be done

Employer
Contact information

What needs to be done

Faith or spiritual leader/organization
Contact information

What needs to be done

Safety deposit box keys and box location

Safe, lock combinations

Location of will and other important items (such as jewelry)

Appendix D: Additional Resources

Along with the American Cancer Society, other sources of information and support include:

National Cancer Institute (NCI)
Toll-free number: 1-800-422-6237 (1-800-4-CANCER) (answers as "Cancer Information Service")
Website: cancer.gov
The National Cancer Institute has information on advance planning and advance directives on their website, as well as pain management, palliative care, and end of life.

Cancer Legal Resource Center
Toll-free number: 1-866-843-2572 (1-866-THE-CLRC)
Website: cancerlegalresourcecenter.org
Cancer Legal Resource Center offers free and low-cost legal information and referrals to people with cancer. If no one answers the phone, leave a number and message for A call back.

Compassion and Choices
Toll-free number: 1-800-247-7421
Website: https://www.compassionandchoices.org/
Compassion and Choices offers worksheets, forms, and help in writing advance directives. It also can help a person approach their families, friends, and health care providers about health care wishes.

Caring Connections, from the National Hospice and Palliative Care Organization (NHPCO)
Toll-free number: 1-800-658-8898 (answers as End-of-Life Consumer Helpline)
Website: caringinfo.org/AdvanceDirectives
Caring Connections lists each state’s requirements for advance directives. The Free Downloads section has a link to "state-specific advance directives" with forms and instructions for each state. Caring Connections also supports people

living with cancer, caring for a sick person, and helps deal with grief a loved one's death

GriefNet (online groups for grief support, with a special site for children only)
Website: griefnet.org

Candlelighters Childhood Cancer Family Alliance
Toll-free number: (713) 270-4700
Website: www.candle.org

The Centering Corporation (information and resources after a loved one dies)
Toll-free number: 1-866-218-0101
Website: www.centering.org

The Compassionate Friends (for those coping with the death of a child)
Toll-free number: 1-877-969-0010
Website: compassionatefriends.org

Substance Abuse and Mental Health Service Administration (SAMHSA)
Mental Health Information Center
Toll-free number: 877-726-4727
Website: samhsa.gov
Substance Abuse and Mental Health Service Administration offers information and help with managing grief, bereavement, depression, and more; call the toll free number to find nearby mental health treatment services

National Institute on Drug Abuse (NIDA)
Phone: 301-443-1124
Phone for people speaking Spanish: 240-221-4007
Website: nida.nih.gov/nidahome.html

The National Institute on Drug Abuse offers information on the science of drug abuse and addiction.

Suicide Prevention Hotline
Toll-free number: 1-800-273-TALK

National Funeral Directors Association (NFDA)
Toll-free number: 1-800-228-6332
Website: nfda.org/consumerresources.php

American Council of Life Insurers (ACLI)
Phone: 202-624-2000
Website: acli.com

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

Appendix E: Coping Checklist for Caregivers and Bereaved

Caring for someone who is sick or dying involves taking on new responsibilities, and can be exhausting. Added to the stress and worry about the person who is ill and all the changes that happen, it can quickly lead to burnout.

So take a moment to look at the statements below, which describe some healthy situations and ways of coping. They'll give you an idea of how well you are holding up. They may offer some thoughts about where you need to make a few changes to care for yourself. The more of these strategies you can use, the better. **If you don't already use all of these ideas, look at ways you can start adding them that appeal to you. They can help you expand your coping skills.**

1. I have a supportive family around me.
2. I pursue a hobby or project for work, church, or my community, etc.
3. I take part in a social or activity group more than once a month.
4. I am within 10 pounds of my ideal body weight for my height and bone structure.
5. I use relaxation methods such as meditation, yoga, or progressive muscle relaxation at least five times a week.
6. During an average week I exercise for at least 150 minutes of moderate intensity activity.
7. I eat a well-balanced, wholesome meal two or three times during an average day. A balanced meal is low in fat and high in vegetables, fruits, and whole-grain foods.
8. I do something enjoyable just for me at least once during an average week.
9. I have a place where I can go to relax or be by myself.
10. I set priorities and manage my time every day (such as deciding what tasks are most important, how much I can and can't do, and by getting help when needed).

Although it can be hard to find the time to do all these things, they can help a lot in keeping some balance in your life during this very stressful time. If your schedule is too crowded, see who you can find to ask for help. If there is no one to help you, talk to your loved one's cancer care team to find out what resources may be available in your area.

Some coping methods aren't as healthy, though. If you use any of these four strategies to help you get by, you may find that over the long term they actually make you less able to deal with important issues in your life. They can also make you less healthy and lead to serious problems. If you need help quitting tobacco, alcohol, or other drugs, talk with your health care provider.

I smoke cigarettes or use tobacco several times a week.

At least once or twice during an average week I use medicines, alcohol, or other substances to help me sleep.

At least once or twice during an average week I use alcohol, medicines, or other substances to reduce anxiety or help me calm down.

I bring work home at least once or twice during an average week.