

Circle Of Life: Cancer Education and Wellness

for American Indian and Alaska Native Communities



American Cancer Society Circle Of LifeSM
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 3: Nearing the End Of Life



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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

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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

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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.

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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

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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

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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

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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

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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

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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.

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- 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).

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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.

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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

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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.

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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.

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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.*