Understanding Cancer

Artist Statement
Stars and Daffodils

In my research for the artwork, I discovered that the daffodil is the flower adopted by the American Cancer Society as a symbol for hope and renewal. The medicine wheel is a symbol for balance in all aspects of our lives. And the stars in the sky symbolize hope. Hope for the day when cancer is no longer a threat to the lives of our people.

Cassandra Leigh Darrough
Paiute-Shoshone
April 19, 2008

A CHR Cancer Education Module

Developed with and for Community Health Representatives (CHRs)
October 2008 Updated 2010

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Funded collaboratively by
National Cancer Institute (NCI)
Quality of Cancer Care Committee (QCCC) and
Indian Health Service (IHS)

ACKNOWLEDGEMENTS

Thank you to the many Community Health Representatives (CHRs) who participated in cancer education and shared their questions and stories.

This cancer education module is based upon '***Path to Understanding Cancer'*** developed for Community Health Aides and Community Health Practitioners in Alaska in 1999 by Debra S. Everson, RN, MN, Anne P. Lanier, MD, MPH, and Melany Cueva, RN, MA. Revised 2005 with additional authors Ann Penvenne, PA-C, Claudette Amadon, RN, Cathy McCann, MA, Mary T. Daly, RN, OCN, Peggy McMahon, RN, CPNP. Revised 2006 by Regina Kuhnley CNM, M Ed. Initial Funding by a NCI R25 (96514) grant to the Alaska Native Tribal Health Consortium.

Thank you to the many people who read, edited, and revised this module to develop a meaningful cancer education resource for CHRs.

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Understanding Cancer

A cancer education module developed with and for Community Health Representatives (CHRs) and other people interested in learning more about cancer.

Section 1 *Self-Care*

Emphasizes the importance of self-care and healthy ways of living.

Section 2 *Wellness Ways to Prevent and Decrease Cancer Risk*

Discusses cancer risk factors and healthy lifestyle choices. Explains the importance of early cancer detection or prevention by having recommended cancer screening exams.

Section 3 *Cancer and Our Genes*

Discusses the role genes play in cancer and the differences among sporadic, familial and hereditary cancers.

Section 4 *Understanding Cancer Basics*

Presents basic cancer information. Discusses possible emotional responses to a cancer diagnosis, types of cancers, methods of diagnosis, and the common medical words used when describing cancer, a cancer diagnosis, and cancer treatment. Some ways to provide comfort and support during a person's cancer journey are also shared.

Section 5 *Cancer Treatments: What to Expect*

Provides information about common cancer treatments, side effects and comfort measures.

Section 6 *Cancer Pain: Assessment and Management*

Provides ways to identify and relieve cancer pain.

Section 7 *Loss, Grief and End of Life Comfort Care*

Discusses loss and grief, and the grieving process. Healthy coping skills are presented.

Resources

Helpful Resources to Learn More

Includes a checklist for evaluating information and helpful organizations to learn more about cancer.

Understanding New Words

Lists definitions of cancer-related words.

Share Your Knowledge *Community Activities*

Presents examples of ways to share cancer knowledge and understanding with the people in your community. Includes directions for a penny game, radio show, and bingo.

WELCOME

Thank you for your willingness to share your wisdom and to learn more about cancer.

As a Community Health Representative (CHR), the knowledge and understanding you share with people is very helpful to **make a difference** in the story of cancer in your community. Working together, we can prevent and decrease the incidence of cancer among American Indian and Alaska Native peoples.

We hope the following information will help you to support the people in your community to understand the ways they can prevent cancer, decrease their cancer risk, and if they are diagnosed with cancer to live well along their cancer journey. No one should have to experience a cancer diagnosis and cancer treatment alone.

As a CHR you may be asked many questions about cancer. If you do not know the answer to a question, use the resources listed in the 'Helpful Resources' section to learn more. Knowledge and understanding about cancer is continually changing as new research is done. This cancer education module was updated in 2010. It is good to update and renew cancer information on a regular basis. You may find that cancer information is regularly updated by organizations and websites found in the 'Helpful Resources' section.

Objectives

After completing this cancer education module, CHRs will be able to:

Discuss ways to reduce cancer risk, including healthy choices about diet, exercise, alcohol, and tobacco use.

Know recommended cancer screening exams and screening guidelines for breast, cervical, colorectal, prostate, testicular, and skin cancers.

Know possible cancer warning signs using the word C.A.U.T.I.O.N.

Understand basic cancer words including biopsy, malignant, benign, tumor, primary site, metastasis, remission, and stage of cancer.

Discuss cancer treatment (surgery, radiation, and chemotherapy) and side effects.

Know cancer resources to find help and learn more.

Experience ways to share cancer information with community

IMPORTANT CHR PCC CHARTING INFORMATION!

1. Chart by using the **CHR Health Problem** code **'CA'** for cancer every time you share any cancer information with a patient or do community education about cancer.

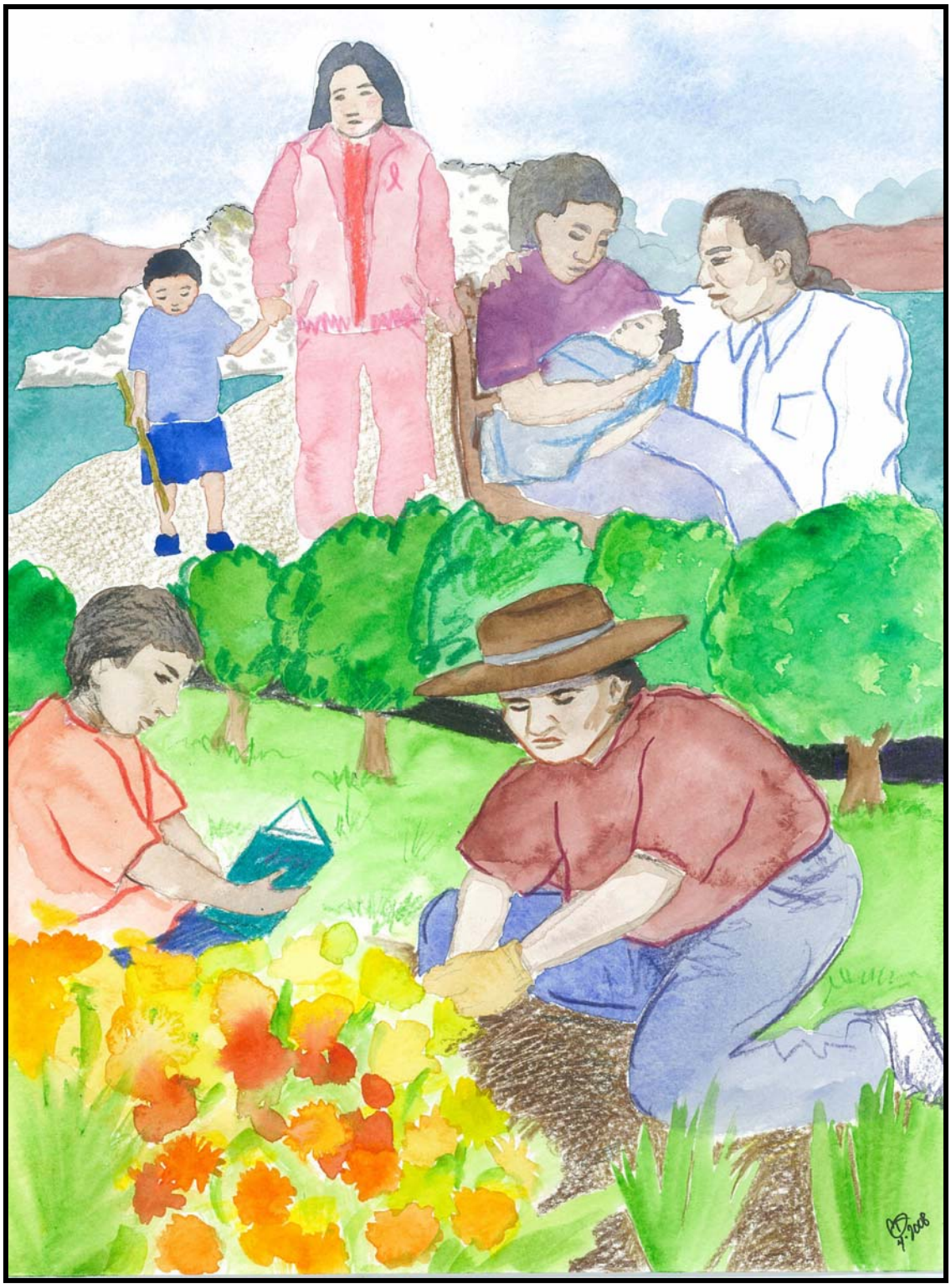
2. Then chart using one of the following **CHR Service Codes**.
   - **'HE'** for health education to increase cancer knowledge and understanding **or** when sharing ways to decrease or prevent cancer including healthy lifestyle choices and recommended screening exams.

   - **'CF' (case find/screen)** whenever you help a patient get a screening exam or make or receive a referral.

   - **'MP'** for monitor patient when the patient is known to have a cancer diagnosis from your reporting facility and a doctor or nurse has requested the CHR to provide care.

   - **'PC'** for any patient care activities, including emotional support, which you perform for a patient who is known to have a cancer diagnosis.

   - **'CM'** for any case management activities, including but not limited to arranging transportation and being a patient advocate, which you perform for a patient who is known to have a cancer diagnosis from your reporting facility.



Living in Balance

Artist Statement
Living in Balance

In this painting, I show many different people engaging in different activities to be well. There is a gentleman working hard in the garden enjoying the day. A teenage boy is sitting, reading a book. A couple is welcoming a new baby into their family. A mother is walking with her son by a lake of green-blue water. They are all enjoying their time with each other and by themselves, showing different yet important aspects of personal and community health.

Cassandra Leigh Darrough
Paiute-Shoshone
April 19, 2008

Section 1

Self-Care

GOALS

Participants will discuss self-care as an important part of patient care. Ways to support personal wellness will be shared.

OBJECTIVES

At the end of this section, each participant will be able to:

DISCUSS pathways for self-care

IDENTIFY ways to include daily, healthy activities to support wellness

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Self-Care

Check Your Understanding

		TRUE	*FALSE*
1.	Stress is a natural part of life.		
2.	You have choices about how you respond to stress.		
3.	Self-care should be last on your list of things to do.		
4.	As caregivers, wellness includes taking care of others balanced with taking care of oneself.		
5.	Wellness choices include living in ways that support physical, emotional, mental, social, and spiritual wholeness.		

Consider this...The following four healthy choices can decrease almost all disease and mortality.

1. **Healthy Diet Including 5 to 9 Servings of Fruits and Vegetables Every Day**
2. **Physical Activity Every Day for 30 Minutes**
3. **Being Tobacco Free.**
4. **Limited or No Alcohol Consumption**

Yesterday is history, tomorrow is a mystery and today is a gift- That's why it's called the present!
~unknown

Another day!

Another chance to make a difference! ~

Lionel 'Quail' Orr Jr., CHR

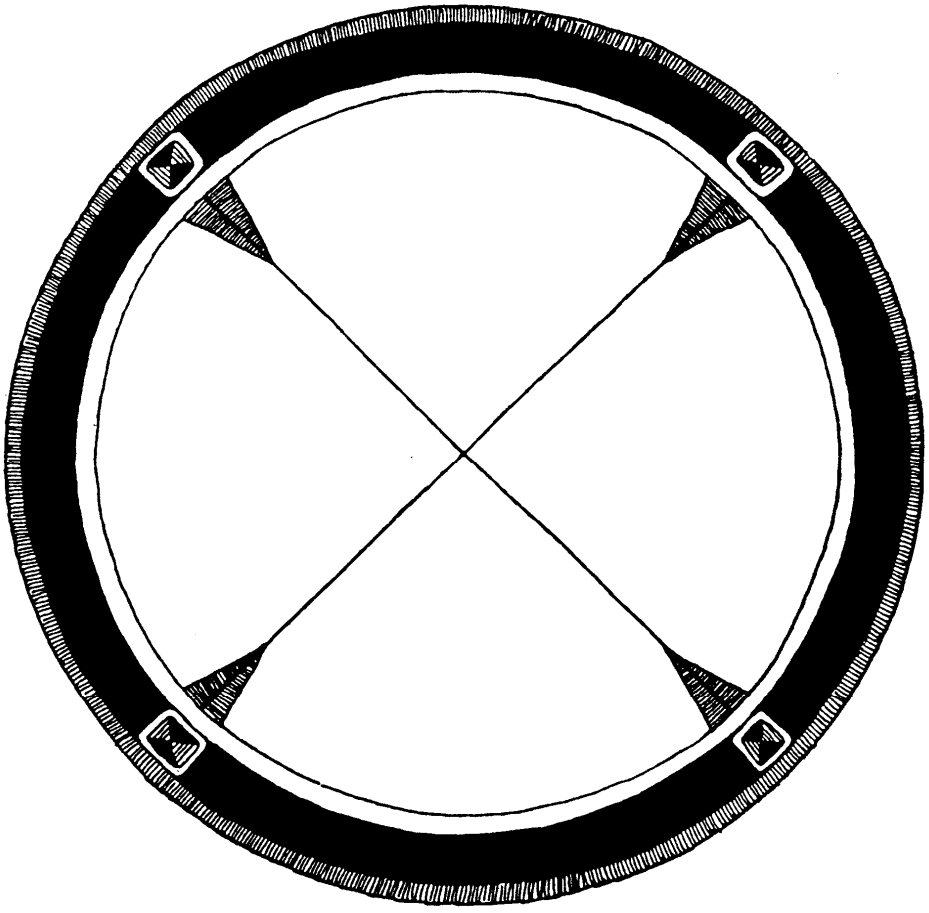
Celebrate Your Contribution to the World

As a health care provider, it is helpful to make time for **your own** wellness, including your Native traditional ways to live in balance and harmony within the spiritual, the natural, and the human realms. What ways of being, thinking, feeling, and doing support your physical, mental, emotional, social, and spiritual wellness?

What renews your spirit and fuels your passion?

Create your own **'Medicine Wheel'** to promote balance and wellness. Write or draw what you do or can do to live well. What part of you needs renewed energy and care?

SPIRITUAL



SOCIAL

EMOTIONAL

PHYSICAL

Self-Care 

Wellness choices include living in ways that support physical, emotional, mental, social, and spiritual wholeness. When our lives are in balance we have more energy to help meet the needs of our patients and ourselves.

What are traditional ways people live in harmony within the natural, spiritual, and human realms?

What have you learned from your Native traditional stories about health and wellness?

What are the traditional stories you tell the next generation about living well along their life journey?

There are common traditional values among American Indian and Alaska Native cultures as shared on the Alaska Native Knowledge Network website. Each adds depth to our understanding of what it means to be whole in the world. Native traditional values include:

- Showing respect to others, each person has a special gift.
- Seeing connections, all things are related.
- Honoring the elders, they show the way.
- Having patience, some things cannot be rushed.
- Praying for guidance, many things are not known.
- Living carefully, things will come back to you.
- Taking care of others, you cannot live without them.
- Sharing what you have, giving makes you richer.
- Knowing who you are, you are a reflection on your family.
- Becoming a happier and healthier person, creating a balance in life: physically, emotionally, mentally, socially, and spiritually.

Take time each day for self-care.

Physical Wellness

- Eat a variety of natural nutritious foods, including 5 to 9 servings of fruits and vegetables every day. Drink water.
- Eat food portions that support your optimum weight.
- Be active. Exercise for 30 minutes every day. Move your Body.
- Get enough sleep, rest, and relaxation.
- Visit your health care provider for preventive health care and recommended cancer screening exams.
- Use safety equipment such as: wearing a seat belt, helmet, flotation vest, sunscreen, eye and hearing protection.
- Protect yourself against sexually transmitted infections.

As caregivers, wellness includes taking care of others balanced with taking care of oneself.

Self-Care

Create a balance in your life: physically, emotionally, mentally, socially, and spiritually.

Emotional and Mental Wellness

- Relax, meditate, pray, or find ways to take at least 15 minutes every day to clear your head.
- Laugh often.
- Have a positive view of life.
- Use constructive ways to express your feelings.
- View change as an opportunity.
- Learn something new every day.

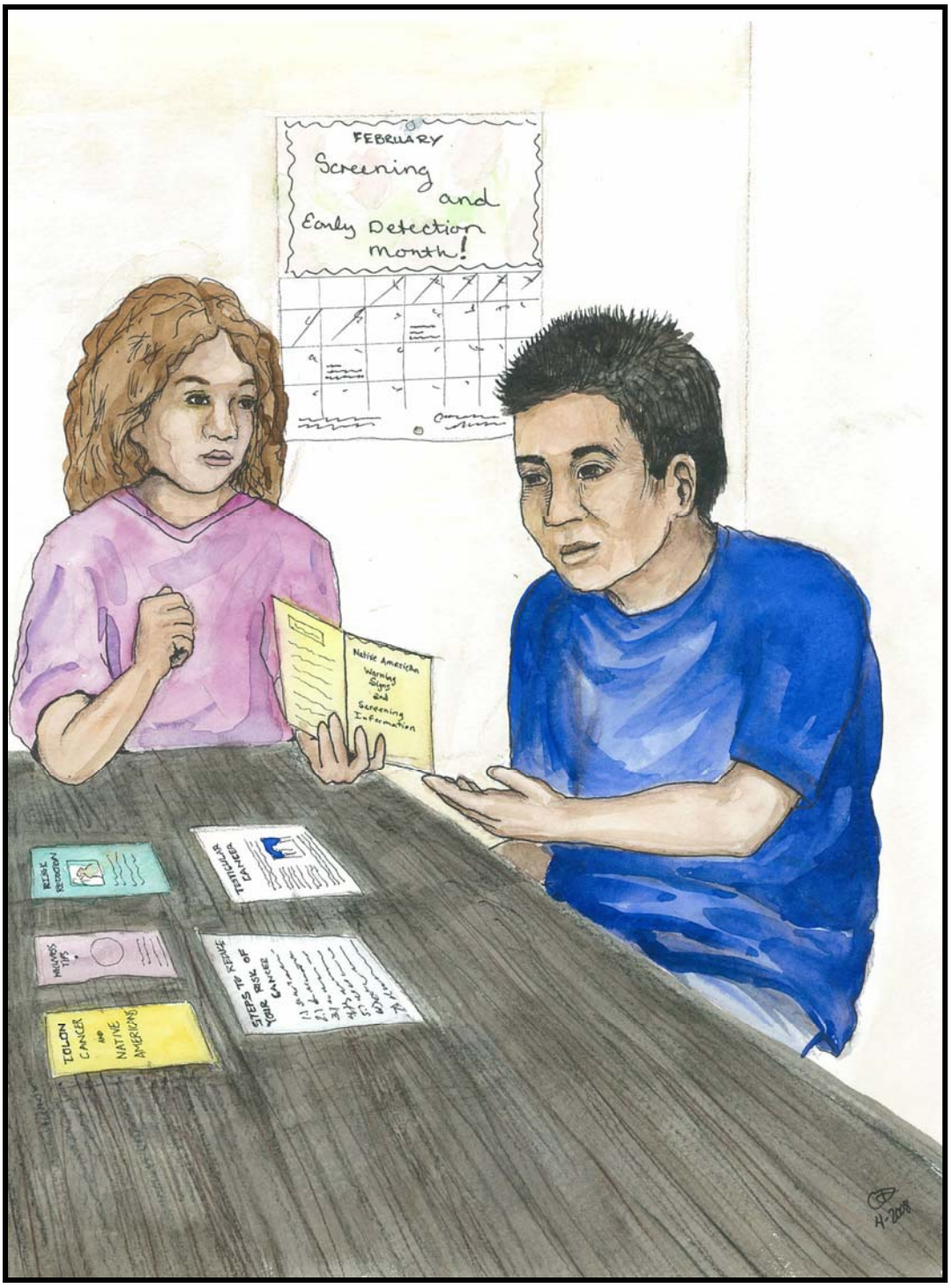
Social Wellness

- Respect yourself and others.
- Enjoy being with family, friends, and elders. Stay connected. Share stories, laughter, and tears.
- Listen.
- Share the gift of dance, music, and song.
- Become involved in making your community a better place to live.
- Develop a support system.

Spiritual Wellness

- Experience nature.
- Take time for prayer and meditation.
- Talk with people who can provide spiritual guidance.
- Every day make time for solitude and quiet.
- Be thankful — Gratitude can help us maintain a balance when life feels overwhelming.
- Celebrate life's journey.

Check Your Understanding answers: 1)T, 2)T, 3)F, 4)T, 5)T



Learning About Cancer Together

Artist Statement
Learning About Cancer Together

A CHR is giving health education to a young man in his teens. The brochures, information sheets, and booklets are all about screening exams, wellness ways, and cancers. I wanted to show that young people are at risk too and most people don't know they can reduce their risk for cancer. That's where the Community Health Representative comes in with education. I know CHRs who give workshops in their communities to raise awareness of cancer, so I wanted to portray their story.

Cassandra Leigh Darrough
Paiute-Shoshone
April 19, 2008

Section 2

Wellness Ways: Prevent & Decrease Cancer Risk

GOALS

Participants will be able to identify cancer risk factors, recognize healthy lifestyle behaviors, and understand the importance of early cancer detection. Recommended screening exams to prevent cancer or decrease cancer risk are discussed.

OBJECTIVES

At the end of this section, each participant will be able to:

DISCUSS healthy choices that decrease cancer risk

IDENTIFY ways to prevent specific cancers

EXPLAIN the importance of early detection for cancer treatment

DISCUSS the barriers and benefits of cancer screening

IDENTIFY screening methods available for specific cancers

KNOW recommended screening guidelines

ANSWER common questions about cancer screening exams and procedures

Wellness Ways: Prevent & Decrease Cancer Risk

Goals & Objectives

Wellness Ways: Prevent & Decrease Cancer Risk

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We need to move from "I"llness to "We"llness, from the individual to the community. ~annonymous

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Cancer Risk Factors & Prevention

Check Your Understanding

		TRUE	*FALSE*
1.	A person has no control over their risk of developing cancer.		
2.	Tobacco use is the #1 cause of cancer.		
3.	Cancer risk increases as you get older.		
4.	Obesity is not a risk factor for cancer.		
5.	A well balanced diet that includes fruits and vegetables reduces the risk of cancer and other chronic diseases.		

As a CHR, what are some ways you can help people in your community to learn about cancer risk factors and prevention?

Possibilities include:

- talking **with** people
- helping to schedule recommended screening exams
- having a community health fair
- having a women's wellness tea or luncheon
- having a men's wellness event
- giving a school or community presentation
- inviting the elders to share their traditional wellness stories
- organizing wellness activities that include the youth and the elders
- starting a walking group, dance group, or exercise activity
- supporting ways to reduce exposure to tobacco smoke and encouraging tobacco cessation, including cigarettes and chewing tobacco
- planting a community garden

If we are to change our behavior, we must first change the way we think. ~ Nancy DeMoss

Making healthy choices may prevent 2 out of 3 cancer deaths.

Cancer Risk Factors & Prevention

This section shares ways to live strong and healthy to prevent cancer or decrease cancer risk. A **risk factor** is anything that increases a person's chance of developing a disease. In the words of a Community Health Aide/Practitioner in Alaska, *"Wellness abides in the heart of the community."* Community conversations about wellness ways are important to support each other in living well throughout our life's journey. Discuss and share your traditional Native wellness ways and how they help to prevent cancer or decrease cancer risk.

There are 7 wellness choices people can make to reduce their risk of developing cancer. These healthy ways may prevent 2 out of 3 cancer deaths.

1. Eat 5 to 9 servings of fruits and vegetables every day. Eat foods low in fat. Drink Water.
2. Decrease alcohol intake or do not drink alcohol.
3. Choose not to have the habit of smoking or chewing tobacco. Avoid exposure to second hand smoke.
4. Keep physically active. Maintain a healthy body weight.
5. Protect your skin from the sun's harmful rays by using sunscreen or wearing protective clothing.
6. Protect against HPV (Human Papilloma Virus).
7. Have recommended cancer screening exams.

Celebrate your wellness ways.
What is one healthy thing you do to take good care of you?

What new ways can you add to support your wellness path? Write it down and tell a friend.

Assess your risk for cancer and other diseases.
To learn more about "Your Cancer Risk" visit the following websites:

'Understanding Cancer Risk' by NCI
www.understandingrisk.cancer.gov

Center for Cancer Prevention
www.yourdiseaserisk.wustl.edu/

Wellness Ways

The choices we make, what we do, and how we live affect our health and well-being. Healthy lifestyle choices include: eating a well-balanced, healthy diet; maintaining normal body weight; being physically active; avoiding use or exposure to tobacco; drinking alcohol in moderation, if at all; practicing safe sex; protecting our skin from too much sun exposure; managing stress, and having recommended screening exams.

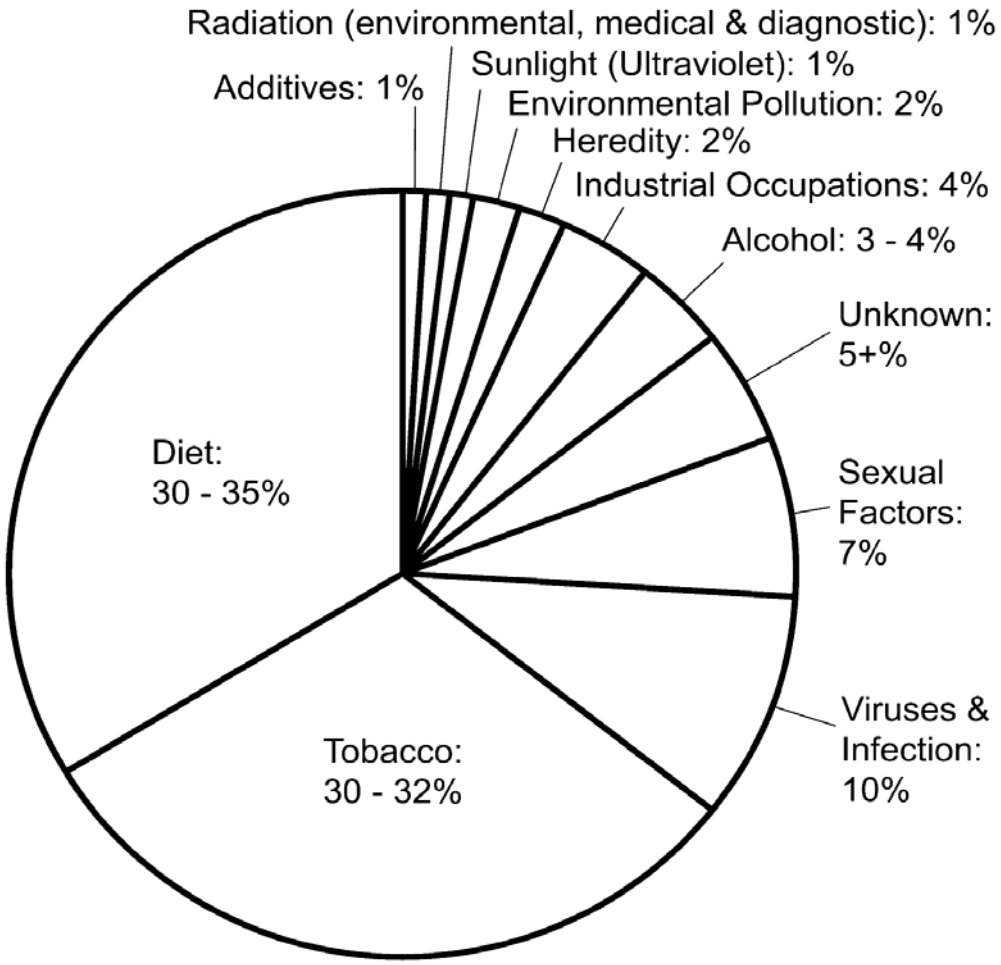
FIGURE 5.1: Cancer Risk Factors with Percentages

Reprinted with permission from Everyone's Guide to Cancer Therapy

Surprise!

Did you know that diet is related to 30-35% of all cancers?

See the chart below.



Cancer Risk Factors & Prevention

Self-Care

Eat at least 5 servings of fruits and vegetables every day. Five is fine but nine is divine!

Have fun picking berries and greens. Learn about the plants in your area.

Self-Care

As a trusted community member and health representative, self-care is an important part of patient care. Add positive energy to your life by identifying healthy activities that make you feel good, then do more of them everyday. Ask yourself: What makes you smile? What fills your heart with love? What small things do you enjoy? Practice healthy ways to cope with stress and anxiety. Increased stress and anxiety over a long period of time can lead to a variety of health problems, affecting your mind, body, and spirit. Stress and anxiety can make you feel tired, decrease your ability to cope, and weaken your natural defenses (the immune system) to fight disease.

Look for ways to live in balance and harmony in body, mind, and spirit. Share stories of wellness. Breathe in slowly, inhaling life's many blessings and breathe out, letting go of stress and tension. Practice slow deep breaths during your day. Make time each day to relax, meditate, exercise, and have fun. Laughter is powerful medicine.

Do at least one healthy activity to take good care of YOU. Before you go to bed tonight, smile knowing you have done at least 1 healthy thing for you.

S.W.E.E.T. Dreams
S - Sleep
W - Water
E - Eat healthy
E - Exercise
T - Think positive thoughts

Nutrition

Today, researchers continue to learn about the connection between good nutrition and good health. Learn about the traditional foods in your area and how they support healthy nutrition. Between 30% - 35% of cancer risk is estimated to be related to an unhealthy diet. **People who are overweight and have a high calorie intake have an increased risk for cancer of the breast, colon, rectum, uterus, kidney, esophagus, and gallbladder.** Many types of cancer may be prevented by eating a healthy diet and maintaining a healthy weight.

Nutrition-related diseases such as heart disease, stroke, cancer, diabetes, and alcoholism are now the leading causes of death among American Indian and Alaska Native peoples. Obesity is also a significant health concern.

The following **Dietary Guidelines** issued by the U.S. Departments of Agriculture and Health and Human Services are recommended **to reduce cancer, heart disease, stroke, and diabetes**:

- Eat a variety of foods of different colors. Have a rainbow of colors in your diet. Eat more red, yellow, orange, dark green, and blue fruits and veggies!
- Balance the food you eat with physical activity and maintain a healthy weight.
- Eat off a small plate. Be aware of portion size.
- Choose a diet with plenty of grain products, vegetables, fruits, berries, and greens.
- Choose a diet low in saturated fat and cholesterol. Choose foods that do not have transfat or partially hydrogenated oil.
- Choose a diet low in sugars. 4 g of sugar = 1 teaspoon of sugar. Avoid low-fat or fat-free foods which have large amounts of sugar or salt. Drink water instead of soda pop.
- Choose a diet moderate in salt, less than 2000 mg daily or 2 g daily.
- Steam or bake foods instead of frying.
- Trim fat off meat before cooking.

Read Labels: When buying food, read the label to help make wise choices. The first ingredient listed in the contents is the item with the highest amount in that product. Other ingredients are listed in decreasing order as to the amount in the product. Watch for high amounts of salt or sodium and sugar or sucrose or high fructose corn syrup (HFCS) and transfats (partially hydrogenated vegetable oil). Choose healthier alternatives.

For a well-balanced meal, divide your plate into quarters or 4 equal parts. One quarter is for carbohydrates or starchy foods such as potatoes, rice, and grains. One quarter is for protein including beans, fish, or game. One half is for fruits and vegetables, including berries and greens.

Alcohol

Drinking alcohol increases the risk for cancer of the liver, breast, larynx, mouth, throat, and esophagus. The risk of developing cancer is greater for people who use tobacco and drink alcohol. From a nutritional point of view, alcohol has negative effects as well. Alcohol keeps the body from burning fat, particularly around the stomach; it has calories, which can add fat to body weight, and it provides no nutrients. If a person has had breast cancer, drinking alcohol increases their risk of recurrence.

Ask elders and people in your community how traditional plants and animal foods are gathered and prepared. What are the medicinal ways plants are used to support wellness?

Cancer Risk Factors & Prevention

Exercise

The ideal physical fitness goal is to exercise for 30 or more minutes every day.

Dance, walk, have fun moving your body every day!

.

Physical Activity

Staying physically active has many benefits. Exercise decreases the risk of developing cancer, heart disease, and diabetes. It also makes a person feel better. Exercise helps to:

- maintain an ideal body weight and prevent obesity by burning fat and reducing fat deposits
- decrease extra hormones that may promote cancer growth
- boost the body's natural defenses and strengthen the immune system
- increase muscle and bone strength
- improve mental health and a sense of well-being

According to American Institute for Cancer Research 2009,

Research Links Physical Activity with Reduced Cancer Risk

Physical activity is associated with an overall:

- 10% to 30% risk reduction for prostate cancer
- 30% to 40% risk reduction for breast, endometrial, and lung cancer
- 40% to 50% risk reduction for colon cancer.

Tip: Starting small can lead to big changes.

Consider the ABCs of healthy lifestyle choices.

A = Add

What can I do at this time, this day to improve my health?

B = Better

What better choice could I make?

C = Change

What change could I make to make this healthier? What do I want or need to do to act on this?

The good thing about behaviors is once you stop them, they are over. It might be what you did yesterday, but it does not have to be what you do today. Once you resolve, "I'm not doing it anymore, I'm worth more than that", a new way of life begins. (Encouragement shared by Dione Harjo.)

Sexual Behavior

The following sexual behaviors increase the risk for developing cervical cancer:

- having sex before the age of 18, and
- having more than one sex partner.

Infection with some strains of the human papilloma virus (HPV) causes almost all cervical cancer in women. The HPV vaccine can help to prevent cervical cancer. This vaccine is given as a series of 3 shots over 6 months and works best if given before a woman becomes sexually active and is exposed to the HPV infection. The vaccine has been widely tested for girls and women ages 9 to 26 and is especially recommended for girls ages 11 and 12. No serious side effects have been found.

Learn more about the HPV vaccine to prevent cervical cancer.

Pap smears continue to be a very important screening test to find changes in cells in a woman's cervix early before the cells have time to develop into cancer. Pap smears are still necessary even if a female receives the HPV vaccine. **HPV infection can occur in both male and female genital areas – even if a condom is being used.** The effectiveness of condom use in preventing HPV infection is not known. **However condoms continue to be an effective way to decrease the risk of other sexually transmitted infections (STIs).**

Tobacco

This section discusses non-ceremonial use of tobacco by American Indian peoples. **Smoking and chewing tobacco account for more deaths from cancer than all other known carcinogens combined.** A **carcinogen** is any substance known to cause cancer. Smoking cigarettes kills more Americans than alcohol, car crashes, suicide, AIDS, homicide, and illegal drugs combined. Tobacco use causes over 30% of all cancer deaths in the United States and 90% of lung cancers. Lung cancer is very difficult to treat. Less than 10% of lung cancer patients live 5 years after diagnosis.

In addition to lung cancer, tobacco use is also associated with the following cancers: nasopharynx (nose and back of throat), lip, oral cavity, pharynx (throat), larynx (voice box), mouth, throat, esophagus, stomach, colon/rectum, bladder, kidney, pancreas, breast, uterus, ovaries, cervix, and acute leukemia.

Tobacco use is the #1 cause of cancer. **Decreasing or eliminating tobacco use is the key to reducing tobacco-related cancer disease and death.**

Cancer Risk Factors & Prevention

Tobacco

Smoking and chewing tobacco account for more deaths from cancer than all other known carcinogens combined.

There are at least 43 chemicals in tobacco smoke known to cause cancer. These chemicals include: ammonia, acetone, arsenic, butane, ethanol, methane, and toluene, to name a few. The effects of tobacco use are increased if there is also exposure to asbestos or alcohol. Risk of cancer from asbestos increases significantly when combined with cigarette smoke. A person who uses both tobacco and alcohol has a much greater risk of developing cancer.

Secondhand smoke, also called passive or environmental tobacco smoke, is a mixture of the smoke given off by the burning end of tobacco products and the smoke exhaled by smokers, which can be inhaled by nonsmokers. It contains the same cancer-causing agents or carcinogens as the smoke inhaled by smokers.

Young children are particularly susceptible to secondhand smoke. **Exposure to secondhand smoke increases their risk for sudden infant death syndrome (SIDS), asthma, bronchitis, middle ear infections, and pneumonia.** People may be exposed to secondhand smoke in the home, car, workplace, and in public places such as bars and restaurants. Maintaining a smoke-free environment is the most effective method for reducing secondhand smoke exposure and the associated health risks.

According to the American Cancer Society 2009:

- 443,000 people in the United States die yearly from illnesses related to tobacco use
- 49,400 non-smokers die every year as a result of exposure to second-hand smoke

What is the traditional role of tobacco among your peoples? How is the sacred use of tobacco different from the habit of smoking or chewing tobacco?

Choosing Tobacco Free

Tobacco is a very addictive substance. Some people are able to stop smoking “cold turkey” without any help, but many people need support, encouragement, and careful planning. Nicotine Replacement Therapy and counseling are also available to help people stop using tobacco.

The tobacco quit line is a helpful resource for people to become tobacco free and the people who want to support their journey.

1-800-QUIT-NOW
(1-800-784-8669)

Tobacco Quit Tips: 1-800-QUIT-NOW

Notice when and why you use tobacco. Keep a notebook and write down with whom, what you are doing, and where you use tobacco.

Plan substitute activities to replace your tobacco habit: walking or other physical activities, listening to music or playing an instrument, things you enjoy doing with your hands.

Make a list of all the reasons you want to stop using tobacco. Keep the list with you so you can look at it often. Post it on mirrors, the refrigerator, and other places you see frequently.

Change your smoking habits: try to smoke with the opposite hand; smoke in only one place (outside!), and don't smoke in the car.

Buy only one pack of cigarettes or one can of chew. Switch to a brand you don't like. Put tobacco in an inconvenient place.

Ask a friend to quit using tobacco with you. If you cannot find one, ask a friend to support you.

Save $$ not used for tobacco in a clear jar; use money to reward yourself for making changes to be tobacco free.

Walk or do some form of exercise every day.

Set a quit date and make it happen!

Celebrate Your Choice to Be Tobacco Free

When you have the urge to use tobacco or overindulge in eating, drinking alcoholic beverages, or use other non-prescribed substances, **Practice the 5 D's:**

DELAY.

DRINK WATER.

DEEP BREATHE.

DISTRACT.

DO SOMETHING ELSE.

Be patient with yourself as you learn how to live without this addictive substance. Involve your family and friends. Some people may feel sleepier, irritable, or have cravings. Share the challenges you may experience with your family and friends to help them provide support and encouragement. Celebrate your healthy choice to stop the habit of tobacco use. Be prepared and know these symptoms will pass.

When Smokers Quit:

Within 20 minutes of smoking that last cigarette, the body begins to heal.

After:

20 minutes: Blood pressure, pulse return to normal, temperature of hands and feet return to normal.

8 hours: Blood carbon monoxide level drops to normal. Blood oxygen level increases to normal.

24 hours: Heart attack risk decreases.

48 hours: Nerves start to restore. Ability to smell and taste improves.

2 weeks to 3 months: Circulation improves. Walking is easier. Lung function increases up to 30%.

1 to 9 months: Sinus congestion, coughing, fatigue, shortness of breath decrease. Cilia are restored in the lungs, increasing ability to handle mucus, clean the lungs, and reduce infection. Body's energy increases.

(American Cancer Society)

Keep your list of reasons for choosing to be tobacco free with you and read them frequently. Share them with friends and family so they can support and encourage you!

Cancer Risk Factors & Prevention

Motivational Interviewing

Support patients, family, and friends to choose healthy ways.

Practice the 5 A's

1. Ask

2. Advise

3. Assess

4. Assist

5. Arrange

Motivational Interviewing Skills

Motivational interviewing is a way to encourage and support people to make healthy choices. To change behavior a person needs to want to change their behavior. Motivational Interviewing is one way to invite people to think about change. Below are examples of questions for conversations about change.

Ask:
"Would it be OK with you if we discussed your tobacco use today?"
If a person says yes, continue with…
"On a scale of 0-10, how ready are you to consider stopping, with 0 being not ready at all and 10 being very ready?"

0	1	2	3	4	5	6	7	8	9	10
Not ready										Very ready

Ask:
"Why did you choose the number you did and not another number?

"Why did you pick a ____ (name the number they gave you) **and not a** ___ (name a number one or two points higher than the original number they gave you)"?

"What would need to be different to make you move to a higher number?"

When talking with the person, you want to:

- Draw out "change talk" or get the person talking about change without you telling them they should change. A sample question to start this is:
  - **How important is stopping tobacco use to you?**
- Find out what makes the person want to stop or not want to stop. Questions to ask are:
  - **What is it you like about using tobacco?**
  - **What is it you do not like about using tobacco?**
- After answering these questions, the person may move toward wanting to stop tobacco use. If the person chooses not to stop tobacco, you have started them thinking about it and he or she may return to discuss the option more with you. Offer your assistance and periodically remind them that you care and are available.

Individual Characteristics

Family history (heredity), gender, or age can influence a person's risk for developing cancer. People with individual characteristics that put them at increased risk for cancer may need to begin screening exams sooner than normally recommended.

Heredity

Currently, about 5% to 10% of cancers are linked to heredity. Only a few hereditary cancer genes related to specific cancers have been identified at this time. Cancers for which heredity is known to be a factor include: breast, colon/rectum, kidney, leukemia, ovary, testis, and a rare form of eye cancer (retinoblastoma).

It is helpful to know your family health history and if anyone in your family has had cancer, as well as the type of cancer and the person's age when they were diagnosed with cancer to tell your provider.

Gender

Women can develop cancers of the vagina, uterus, and ovaries, while men can develop cancers of the prostate, testicles, and penis.

Men and women can both get breast cancer. However, breast cancer in men is less than 1% of all cancers and in women breast cancer accounts for approximately 20% of all cancers. According to the American Cancer Society, during 2009 approximately 2,000 men and 254,650 women in the U.S. were diagnosed with breast cancer.

Age

The risk of developing cancer increases with age. One of the reasons we are seeing more cancer is because people are living longer. **For most common cancers (breast, colorectal, and prostate), a person's risk increases after age 50.** Elders experience about 60% of all new cancer diagnosis and 70% of cancer deaths.

Individual Characteristics

There are 7 wellness choices you can make to reduce your risk of developing cancer.
These healthy choices may prevent 2 out of 3 cancer deaths.

1. *Everyday eat 5 to 9 servings of fruits and vegetables. Eat foods low in fat.*
2. *Decrease alcohol intake or do NOT drink alcohol.*
3. *Choose to be tobacco free. Avoid exposure to second hand smoke.*
4. *Keep physically active. Maintain a healthy body weight.*
5. *Wear sun protection.*
6. *Prevent HPV.*
7. *Have recommended cancer screening exams.*

Cancer Risk Factors & Prevention

CAUTION

Cancer Warning Signs

Share your traditional stories to learn wellness ways.

C.A.U.T.I.O.N. Cancer Warning Signs

(adapted from American Cancer Society, 1999, 2007).

The word CAUTION will help you to remember the following warning signs of cancer. Various signs are associated with cancer but they can also be symptoms of other diseases. Since these may indicate cancer or another condition, it is important if you notice changes within your body to see your health care provider. The following story invites us to learn wellness ways from our elders. Think about the stories you know and how they can support you or your patients along a pathway for wellness.

An Inupiaq elder studies the moon at night. Qungununa, his small granddaughter, asks "Aapa, why do you look at the moon and sky for such a long time?" Aapa tells her that the moon and sky are warning him of the coming winter storm and that he should take precautions when he goes out to hunt the next day. Little Qungnuna asks how does the moon and sky speak to him. The elder replies "See the rainbow-like haze spread out far around the moon; when you see that it means watch out for coming blizzards."

By becoming comfortable and knowledgeable about our bodies, it is easier to notice changes early which may be warning signs for diseases such as cancer. In this traditional story, Aapa shared his knowledge and wisdom about nature's warning signs with his granddaughter. **His words did not "bring on" the blizzard but served as a warning to better prepare for future possibilities.** Aapa's story helps us understand the importance of recognizing warning signs, not only in nature, but also in the health and wellness of our bodies**.** Knowing and observing changes within our bodies and seeing and telling a health care provider are important ways to keep our bodies strong and healthy.

As a CHR, you can learn about cancer warning signs and share "C.A.U.T.I.O.N." with your patients and the people in your community. Help people become better prepared to find and report body changes early when they can be best treated!

C.A.U.T.I.O.N

Change in bowel or bladder habits
Changes in bowel function include diarrhea, constipation, size of stool, or blood in stool. Bladder changes include having trouble urinating and urinating more often than usual.

A sore that does not heal
This includes any open sore or irritation of the skin any where on the body, or sores that heal and then break down again. Cracks in and around the mouth which do not heal or persistent white patches in the mouth.

Unusual bleeding or discharge. Unusual menstrual bleeding, any bleeding between menstrual periods, blood in the urine, coughing or spitting up blood, or bleeding from the rectum or anus (may look black or red).

Unexplained weight loss. Weight loss that is not caused by dieting or exercise.

Thickening, lump, or swelling in the breast or any other part of the body
Persistence of swollen lumps or lymph nodes after several weeks.

Indigestion or difficulty swallowing
Any pain or difficulty in swallowing, a feeling of fullness, or persistent nausea and vomiting.

Obvious change in a wart or mole
Change in size, shape, thickness, or color of a mole or wart. Moles and freckles should not bleed or drain.

Nagging cough or hoarseness
Any new hoarseness or cough which does not go away or any change in a “smoker’s cough”.

Some signs are associated with cancer but they can also be signs of other health problems. It is important to discuss health changes with a health care provider.

Check Your Understanding answers from page 2-3:
1)F, 2)T, 3)T, 4)F, 5)T

C.A.U.T.I.O.N.

Cancer Warning Signs

Remember, most cancers do not cause pain or other symptoms when they first start and are small.

Cancer Screening & Detection

Check Your Understanding

		TRUE	*FALSE*
1.	All cancers can be detected at an early stage.		
2.	Barriers to cancer screening exams may include lack of knowledge, fear of cancer, and modesty.		
3.	The most common cancer among young men, ages 15 to 35, is testicular cancer.		
4.	Early cancer detection includes monthly self-examinations and recommended cancer screening exams.		
5.	Most breast lumps are cancer.		
6.	Cervical cancer can be prevented.		
7.	A colonoscopy is a screening exam used to find stomach cancer.		
8.	There are often NO early symptoms of colorectal cancer.		

What can you do as a CHR to support people in your community to have recommended wellness screenings to prevent cancer or find cancer early when it can be best treated?

Possibilities include:

- Tell people about recommended screening exams
- Listen to why people choose not to have a screening exam and help to decrease their barriers
- Offer to help make an appointment
- Offer to go to the appointment with the person
- Help to arrange or provide transportation to the appointment

Early Detection

What is early detection?

Early detection means finding cancer in its early stage, when it is limited to one area of the body, before it has time to spread beyond the organ where it first started to grow.

Survival rates improve when cancer is found and treated early.

Why is early detection important?

The goal of early detection is to find and remove or destroy cancer before it grows and spreads. This means finding the cancer before people start to have pain and other symptoms. Most cancers do not cause pain or other symptoms when they first start and are small. If found early, cancer can be treated more effectively and the person has a better prognosis or outcome.

The BEST way to treat cancer is to find and treat it EARLY!

What are the basics of early detection?

Currently, not every cancer can be easily detected at its earliest stage by a screening exam. However, several screening exams and procedures have been developed for specific cancers. When screening exams are done as recommended, cancer can be found early before pain or symptoms occur. Cervical and colorectal cancers can be prevented by removing abnormal cervical cells and polyps in the colon early before they have time to become cancer. Screening guidelines may change for specific cancers. It is important to continue to update your knowledge. Talk with the health care providers at your clinic to learn what screening exams and how often are being recommended at your clinic to prevent or find changes early that may be cancer.

Basics of early detection are:

1. Do monthly self-examination.
2. Have recommended screening exams regularly for specific cancers.
3. Recognize warning signs and see your health care provider immediately.

Screening Exams: Barriers & Benefits

Barriers to screening exams

By taking the time to listen and respect a person's concerns and identify barriers to screening tests and procedures, you can help decrease fear and increase understanding. A barrier to cancer screening is anything that makes it hard for a person to have a cancer screening exam. It is important to ask, listen, and learn what people feel are barriers to having wellness screening exams. Some barriers can be eliminated, while others are beyond your control. It is important to support and help people understand the importance of early cancer detection, provide appropriate services when available, and then allow each person to make her or his own health care choices to support wellness.

What are some cultural barriers that may affect people's choices about having screening exams?

Common barriers to screening exams may include:

Lack of Knowledge: Many people do not understand cancer, the importance of cancer screening exams or how to do self-exams effectively. Sharing information about methods of early detection, including when and how often screening exams are recommended, is helpful.

If there is no cancer, a screening exam can be reassuring!

Fear of a Cancer Diagnosis: If cancer is present and a person avoids an early diagnosis and treatment the cancer will continue to grow. If there is no cancer, a screening exam can be reassuring! Some screening exams (Pap test, colonoscopy or sigmoidoscopy) help to prevent cancer by finding and removing abnormal cells before they become cancer. Early detection is the first and most important step to survival. When cancer is found and treated early, cure or remission is possible.

Early detection is the first and most important step to survival.

Modesty: Women or men can request a female or male provider or have a CHR, friend or family member be with them during the exam. Sometimes a person may have a history of sexual abuse, which may make a person uncomfortable with having an exam. Talking about a person's concerns and listening in a respectful and confidential manner is often helpful.

Not a Priority: Sometimes people say they are too busy or do not have enough time to have a screening exam, especially when they feel healthy. Others feel "it's not going to happen to me". Lack of child-care and transportation can also be barriers. A helpful way to support someone to have a screening exam is to lovingly encourage them to make an appointment and support them in ways needed for them to keep their appointment.

Cancer Screening & Detection

Screening Exams: Benefits

Recommendations for screening exams are based upon a person's age, risk factors, and family history. If warning signs are noticed it is important to see and tell your health care provider. Early cancers may have NO signs or symptoms. **It is important to encourage people to have regular, recommended screening exams when they feel healthy to stay healthy.**

Benefits of having a screening exam

- You are including prevention in your pathway of wellness.
- You are actively taking care of your health.
- You may feel a sense of relief.
- You are a positive example for your family and friends.

Helpful ways to share information

1. Listen to a person's story and concerns.
2. Talk one-on-one with the person.
3. Be respectful.
4. Establish trust.
5. Be honest and share helpful experiences.
6. Explain information in ways the person understands.
7. Support people to hear information in new ways.
8. Invite people to share their ideas about what is hard to talk about or culturally taboo.
9. Have fun learning together!

Talking Points:

The sooner cancer is found and treated, the better a person's recovery. The chances that cancer will be found early are improved by having recommended screening exams, doing monthly self-exams, and being aware of body changes. Cancer in its early stages can be present even if a person feels healthy and has no symptoms.

Colorectal screening is recommended for both men and women. Screening exams and tests for testicular and prostate cancers are recommended for men. Breast and cervical screening exams are recommended for women.

Being aware of how your body looks and feels will help you notice changes early. Testicular self exams (TSE) and breast self exams (BSE) are two types of self-checks that help people to become more familiar with what is normal for their body.

A health care provider can recommend the best screening plan based upon current guidelines, the person's age, medical history, family history and personal history of cancer.

Cancer Screening & Detection

Colon/rectum Screening

There are NO early warning signs for colorectal cancer.

Men and Women's Health

Colorectal Cancer Screening

March is colorectal cancer awareness month. Colorectal cancer is the second leading cause of cancer death for many American Indian and Alaska Native people, yet it can be prevented. The words colorectal cancer mean cancer of the colon or cancer of the rectum. The colon, also called the large intestine, removes water and nutrients from partially digested food. The rectum is the lowest end of the colon.

There are NO early warning signs for colorectal cancer. However, late signs in the cancer's development may include a change in bowel habits, change in shape of stool, blood in the stool, or a constant feeling like you have to go to the bathroom.

Why have a colorectal screening exam?

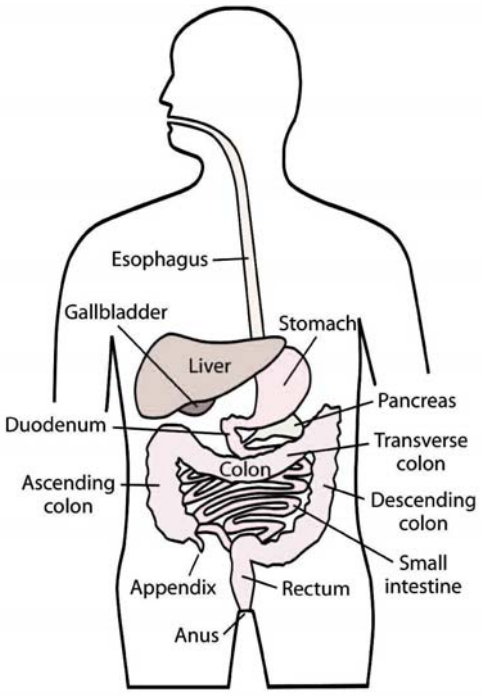
To prevent cancer by removing **polyps** (small noncancerous growths) before they become cancer. If there is already cancer, find it early when it can be best treated.

Frequency: Men and women start colorectal screening at age 50. If you have a mother, father, sister, or brother who had colorectal cancer you need to begin screening at age 40 or younger. Talk with your health care provider.

The United States Preventive Task Force recommends against routine screening for people age 76 to 85 but some people may benefit. The task force does not recommend screening exams for people older than age 85.

Methods: Screening exams for colorectal cancer include:
1. A test for microscopic blood in the stool, Fecal Occult Blood Testing, every year, or
2. Sigmoidoscopy every 5 years with fecal occult testing between having a sigmoidoscopy or
3. Colonoscopy every 10 years to examine the entire colon.

A **sigmoidoscopy** examines the rectum and the descending colon or sigmoid colon. If a polyp is found during a sigmoidoscopy, a colonoscopy will need to be done to check all of the colon. Polyps are not removed during a sigmoidoscopy.



A **colonoscopy** examines the rectum and ALL of the colon. A mild sedative may be given for a colonoscopy. During the exam, your health care provider may remove polyps or small pieces of tissue, called a biopsy. A biopsy is examined under a microscope to look for cancer cells by a specially trained doctor, called a pathologist.

Before either procedure, patients are given a 'prep' –medications to completely empty the colon so the tissue lining of the bowel and rectum can be seen. Both procedures use a flexible fiber-optic scope to see the inside lining of the colon and rectum.

Skin Cancer Screening

May is skin cancer awareness month.
To protect skin from the sun's harmful rays, people wear protective clothing, hats and long sleeve shirts, and sunscreen with an SPF (sun protection factor) of 30. Using tanning booths is **not** recommended.
Moles: For concerns about a mole use the ABCD method to help decide if it needs to be checked by a provider. If you answer yes to the following questions, have the mole checked by a provider.

A=Asymmetry Does the mole look different on either side?

B=Border Is the border jagged or uneven?

C=Color Are there varied colors in the same mole?

D=Diameter Is the mole growing?

Sores: Any sore that does not heal needs to be reported.

If a person has a rash on one nipple and not the other nipple and the rash is not getting better, and is not responding to medical treatment, it may be Paget's disease a type of breast cancer. The person needs to be seen by their health care provider.

Men's Health

Prostate Screening

September is prostate cancer awareness month.

The prostate is a gland surrounding the neck of the bladder and the urethra. The prostate gland adds fluid to sperm.

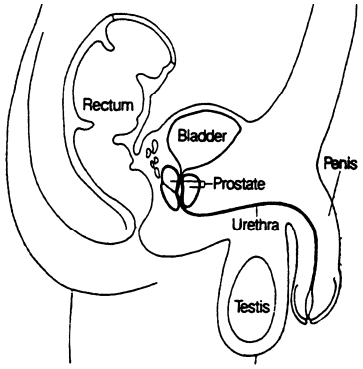
Frequency: It is helpful for men to talk with their provider to learn what is best for their health. Guidelines for routine screening may vary. A prostate-specific antigen (PSA) blood test and a digital rectal examination (DRE) may be recommended yearly for men starting at age 50. For men with a family history of prostate cancer, prostate screening may begin at age 40 or 10 years before the person's father or brother was diagnosed with prostate cancer.

There is not agreement that every man age 50 and older should have prostate cancer screening but there is agreement that every man age 50 and older should discuss this with his provider. Ask men ages 50-75 without a family history of prostate cancer if they have discussed the risks and benefits of prostate screening with their provider. The United States Preventive Task Force does not recommend prostate screening for men older than age 75.

Method: A blood test may be ordered to screen for prostate cancer. The PSA level may be elevated in men who have prostate cancer, an enlarged prostate, or an infection in the prostate. For more accurate results, the blood test is done before doing a digital rectal exam.
A rectal exam is done to feel for abnormal lumps in the prostate, which may be cancer. The health care provider puts a gloved finger into the patient's rectum to feel the prostate through the wall of the rectum and check for any hard or lumpy areas. The man may feel mild pressure in his rectal area during the procedure.

Prostate Screening

An elevated PSA blood test does not mean you have prostate cancer, but it does require further evaluation.

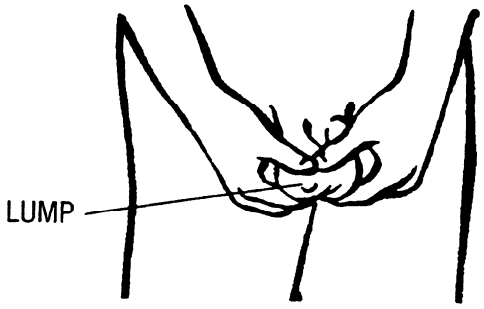


Cancer Screening & Detection

Testicular Cancer

Testicular cancer is rare, but it is the most common cancer in men ages 15 to 35.

NOTE: The epididymis, the soft tube-like structure at the back of the testes, should not be confused with a tumor.



Testicular Health

April is testicular cancer awareness month. Testicular cancer is among the most curable types of cancer when diagnosed and treated early. Teaching young men about testicular self-exams and the importance of early detection and treatment can save a young man's life. The testicles are the organs in males that produce sperm and the male hormone, testosterone. They are suspended from the body in the scrotal sac behind the penis.

What are the risk factors?
Men who are born with an undescended testicle (the testicle has not moved down into the scrotum where it belongs) have a 5 times higher risk of developing testicular cancer. If the testicle does not move into the scrotum by itself within the first year of life, it may require surgery. Men with a father or brother who had testicular cancer have a higher risk for developing testicular cancer. Men who have had testicular cancer in one testicle are at a higher risk of developing cancer in the other testicle.

Signs or symptoms of testicular cancer may include the following:

- A painless lump or irregularity in either testicle.
- A change in the size or shape of a testicle.
- Swelling or feeling of heaviness in the testicle.
- Pain or discomfort in the testicle.
- Pain or discomfort in the lower abdomen or groin.

Not all abnormal conditions are testicular cancer, but it is important for young men to report any changes to their health care provider for an exam and evaluation.

Testicular Exam

Men do a testicular exam once a month after a warm bath or shower. The heat causes the scrotal skin to relax, making it easier to feel anything unusual about the testes. If a man does a monthly exam he will learn what his testicles normally feel like and will be able to identify any changes in the tissue early. A monthly testicular exam can increase the chances of finding abnormal changes in the testicles early which may be cancer.
To do a testicular self exam, examine each testicle separately. Using both hands, hold the testicle between the thumbs and fingers. Apply gentle pressure to feel each testicle on all sides. A normal testicle is egg-shaped, somewhat firm to touch, and should be smooth and free of lumps. Feel for lumps and areas of unusual firmness anywhere on the testicle. Abnormal lumps are usually painless and about the size of a pea. If an abnormality is found, tell your health care provider immediately. When testicular cancer is found early, it is one of the most curable cancers.

Women's Health

Breast Health

October is breast cancer awareness month. Breast self awareness, clinical breast exams (CBE), and mammograms are three ways for women to find breast changes early that may be breast cancer.

An effective breast exam has two important parts: 1) looking at the breasts and 2) feeling the breast tissue for changes and swollen lymph nodes under the arm and above and below the collarbone.

A woman of any age should see her health care provider if she notices

- a breast lump
- a change in one breast and not the other
- change in breast skin color
- puckering or dimpling of the breast
- spontaneous nipple discharge or leaking (not breast milk)
- a rash or crusting on one nipple and not the other nipple
- turning in or inversion of the nipple that used to be pointed outward.

Although 8 out of 10 breast lumps are not cancer, you cannot tell just by looking. It is important to report all changes to a health care provider.

A woman's risk of developing breast cancer increases with age. Over half of all women diagnosed with breast cancer are over age 50. Just being a woman and getting older are the two biggest risk factors for developing breast cancer. Other breast cancer risk factors include:

- A first degree relative (mother, father, sister, brother, or child) with breast cancer.
- Personal history of breast cancer.
- Having no children or giving birth after age 30.
- Early menarche (less than 12 years of age).
- Late menopause (greater than 55 years of age).

Being overweight, eating a high fat diet, drinking alcohol, and using tobacco increase a person's risk of developing breast cancer.

Breast Self Awareness

Breast self checks help people become comfortable and knowledgeable in the way their breasts normally look and feel.

Breast self awareness, clinical breast exams, and mammograms all help to find breast cancer early when it can be best treated.

Cancer Screening & Detection

Breast Exam

The shape, size, and feel of breasts will be influenced by monthly menstrual cycles, childbirth, breast-feeding, birth control pills, hormone replacement therapy, menopause, weight changes, and age. The key for people is to learn what is normal for them and to notice changes early to discuss with their health care provider.

Frequency: A woman examines her breasts every month, at the same time each month. For a woman who is still menstruating, it is best to do a breast exam 3-5 days after her menstrual period is over. Breast tissue is less sensitive and less lumpy at this time. Women who are no longer having menstrual periods can pick a day that is easy to remember, such as the first day of the month, her day of birth, or when she pays the bills.

If a woman does regular breast exams she will become more comfortable and confident with her skills to see or feel changes in her breast tissue early.

Clinical Breast Exam (CBE)

A clinical breast exam is done by a trained health care provider. The health care provider looks at and feels the breast tissue for any changes or abnormalities.
Frequency: A CBE is done every three years for women ages 20 to 39 and every year for women 40 and older.

The B

A simple and beautiful reminder of hov ' breast exams, and mammograms can save you **fun.**

Materials Needed:

Two: 3/16" beads
These lumps are the average size of lumps found by regular and repeat mammograms

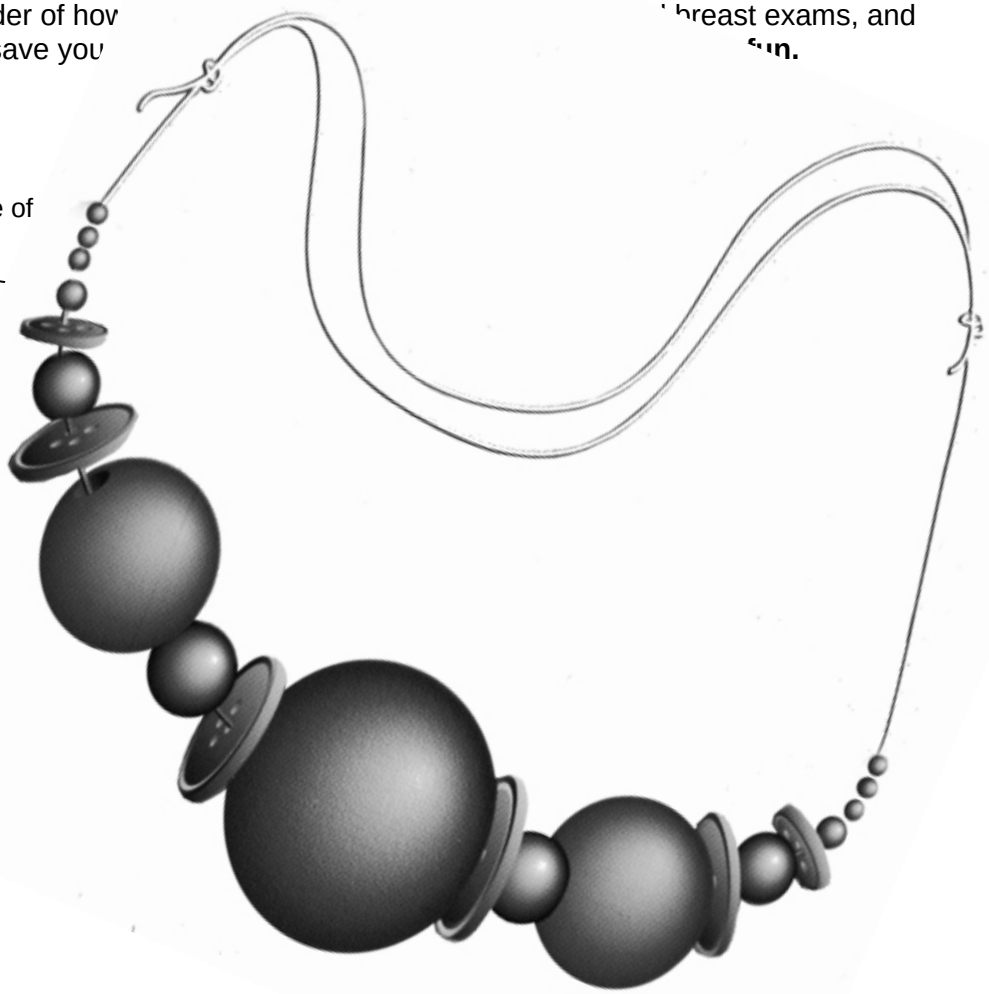
Two: 3/8" beads
This is the average size lump found by first mammograms

Two: 1" beads
This is the average size lump found by occasiona breast self exams

Two: ½" beads
This is the average s found by regular br

One: 1 ½" bead
This is the average women untrained in breas

Use buttons for spacing.



Mammograms

A mammogram is a special x-ray of the breast. Two x-rays are taken of each breast: one is top to bottom, and the other is side to side. More views may be needed if the person's breasts are large or if the mammogram is being done to check a suspicious lump. The mammogram is done by a radiology technologist, who is trained and licensed to do mammograms.

Do not wear deodorant or talcum powder before having a mammogram. The aluminum in deodorant may interfere with the mammogram results.

Frequency: The United States Preventive Task Force recommends women begin having a screening mammogram every 1-2 years at age 40. The American Cancer Society and the National Cancer Institute recommend women have a mammogram every year beginning at age 40.

If a woman's mother, father, brother, or sister was diagnosed with breast cancer, the woman may need to begin having earlier screening exams, 10 years before the age the relative was diagnosed. If the woman's mother was diagnosed with breast cancer at age 40 the woman may need to begin screening at age 30. If the family member was diagnosed at age 60, the woman still needs to begin having a screening mammogram at age 40.

A mammogram can find a lump when it is the size of a small seed, before it can be felt by a woman or her health care provider.

Mammography may miss some breast changes. For this reason, a woman is encouraged to do regular, breast self exams and have regular clinical breast exams by her health care provider.

Men who notice a breast lump or other changes of concern need to see their health care provider for a complete exam. Men with a breast health concern may have a mammogram to help identify abnormal breast changes.

A mammogram can find breast changes early before they can be felt.

Cancer Screening & Detection

Mammogram Questions

Finding breast changes early is important for breast cancer treatment and survival.

Common Questions about Mammograms

Why should I get a mammogram if my breasts feel fine?
A mammogram can find breast changes which may be cancer before they can be felt. A yearly mammogram is an opportunity for a woman to take care of herself, stay healthier longer, and become a role model for her family and friends. It is much easier to treat breast cancer when it is found early.

Does having a mammogram hurt?
A mammogram may cause discomfort while the breasts are being compressed for the x-ray. The pressure is necessary to take the best x-ray or picture of the breast tissue. Compression does not damage breast tissue in any way. Any discomfort will be short term. Ways to reduce discomfort include taking a Tylenol before your mammogram or scheduling the mammogram 3-5 days after a menstrual period when breast tissue is less tender.

Will the radiation from a mammogram cause cancer?
The amount of radiation exposure from a mammogram is very low. The radiation that you receive during one mammogram is the same amount you receive from your natural surroundings during a 3 month period of time. (American Cancer Society)

If no one in my family has had breast cancer do I still need to be concerned about developing breast cancer?
Yes, even if no one in your family has had breast cancer it is an important part of your health care to have clinical breast exams and a mammogram every year once you turn 40. About 90% to 95% of women who develop breast cancer do not have a family history of breast cancer. Breast cancer is the most commonly diagnosed cancer among all women. The biggest risk factor for developing breast cancer is just being a woman.

What if there is a history of breast cancer in my family?
Talk with your family to learn your family medical history. Through our family we pass on our traditions and stories about ways to live strong and healthy. We also pass on our genes.

Cancer can be in families. Learn if someone in your family has had cancer, what kind of cancer, and at what age they were diagnosed.

People with a first degree blood relative (mother, father, sister, brother, son, or daughter) with breast cancer are at higher risk for developing breast cancer. About 5% to 10% of breast cancers are linked to genes known specifically to cause breast cancer. It is important to discuss your family history with your health care provider, get regular mammograms (you may be advised to start before age 40), have yearly clinical breast exams, and do monthly self breast exams.

If there is a lump in my breast, does that mean I have breast cancer?
Not necessarily. 8 out of 10 lumps found in the breast are benign (not cancer). But you cannot tell if it is cancer just by feeling. A tissue biopsy is the only way to know for sure if a lump is cancer.

Why do I need to get a mammogram every year?
Mammograms can show breast changes, which may be cancer even before they can be felt on exam. By comparing mammograms each year, it makes it easier for the radiologist to see early changes in the breast tissue which may be cancer.

Cervical Health

A Pap smear test can find cervical cell changes early before they have time to become cancer. Having regular Pap smears can prevent cervical cancer. For the Pap smear exam, the health care provider places a speculum in the vagina to see the cervix. A sample of cells is collected from the cervix and examined under a microscope for cancer or other abnormal cells. By finding and treating abnormal cervical cells early, cervical cancer can be prevented.

During the pelvic exam, the health care provider feels for any change in size or shape of the uterus, vagina, ovaries, fallopian tubes, and bladder. This exam is done by placing the gloved index and middle fingers of one hand into the vagina while the other hand is placed gently and firmly on the abdomen to feel the pelvic organs.

A woman has a Pap smear test every year or as recommended by her health care provider

- approximately 3 years after becoming sexually active or
- beginning when the woman is age 21

According to the United States Preventive Task Force, women can stop having Pap smear exams at age 65 if they have had regular Pap smear exams in the previous 10 years and are not at increased risk for cervical cancer. Risk factors for cervical cancer include: having HPV, more than 1 sex partner, and using tobacco.

If the Pap smear is abnormal or "unsatisfactory", it is very important that the woman returns for another exam. "Unsatisfactory" result means the laboratory did not have enough cells for the test to be completed or the specimen was handled incorrectly. If the Pap smear showed an abnormal result, it could be due to an infection or irritation of the cervix or a precancerous condition. The woman needs to return for a repeat exam to determine the cause and be treated if necessary. It is very important to complete follow-up visits.

When a woman's Pap smear is abnormal, a **colposcopy exam** may be recommended. A colposcopy is a visual examination of the cervix using a vaginal speculum, bright light, and special binoculars to magnify a woman's cervix. During colposcopy, a biopsy may be taken of cervical tissue that looks abnormal. This tissue is then looked at under a microscope by a specially trained doctor called a pathologist.

Common Questions about Cervical Health

Could I have cancer of the cervix and not know it?
Yes. There is usually no pain or symptoms, such as bleeding or discharge, during the early stage of cervical cancer. Therefore it is important to get a Pap smear every year or as recommended by your health care provider.

Does a Pap smear hurt?
Women may experience a small amount of cramping or discomfort during a pelvic exam and Pap smear. However, the procedure takes very little time and it can save a woman's life.

Since the 1940s, when the Pap smear was first developed, hundreds of thousands of women's lives have been saved because this screening test finds abnormal cell changes before they become cervical cancer.

Cancer Screening & Detection

Cervical Health

There is a vaccine to prevent cervical cancer. Ask your health care provider, to learn more about the HPV vaccine.

Why do women have to get Pap smears after they stop having children and go through menopause?

Cervical cancer can happen to a woman at any age. Yearly Pap smears can find cervical changes early before they become cancer.

Does a woman who has had a hysterectomy need to have Pap smears?

A woman needs to discuss her situation with her health care provider. The answer depends upon the reason she had the hysterectomy. All women, even if they do not need a Pap smear, still need to have a yearly pelvic exam.

Exciting news! There are vaccines to prevent the majority of cervical cancers!

HPV, or the human papilloma virus, causes nearly all cervical cancers. There are about 35 different types of HPV, and not all types of HPV cause cervical cancer. HPV is transmitted through sexual contact. If girls and women are vaccinated prior to their first sexual experience, the majority of cervical cancers can be prevented.

The vaccine is most effective when given before a person is exposed to HPV. Consequently, the vaccine is especially recommended for girls ages 11 and 12 before they become sexually active to prevent becoming infected with HPV at some time in their life. At this time, the HPV vaccine is recommended for girls ages 9 to 26. The vaccine is being tested for women older than age 26 and for boys and men.

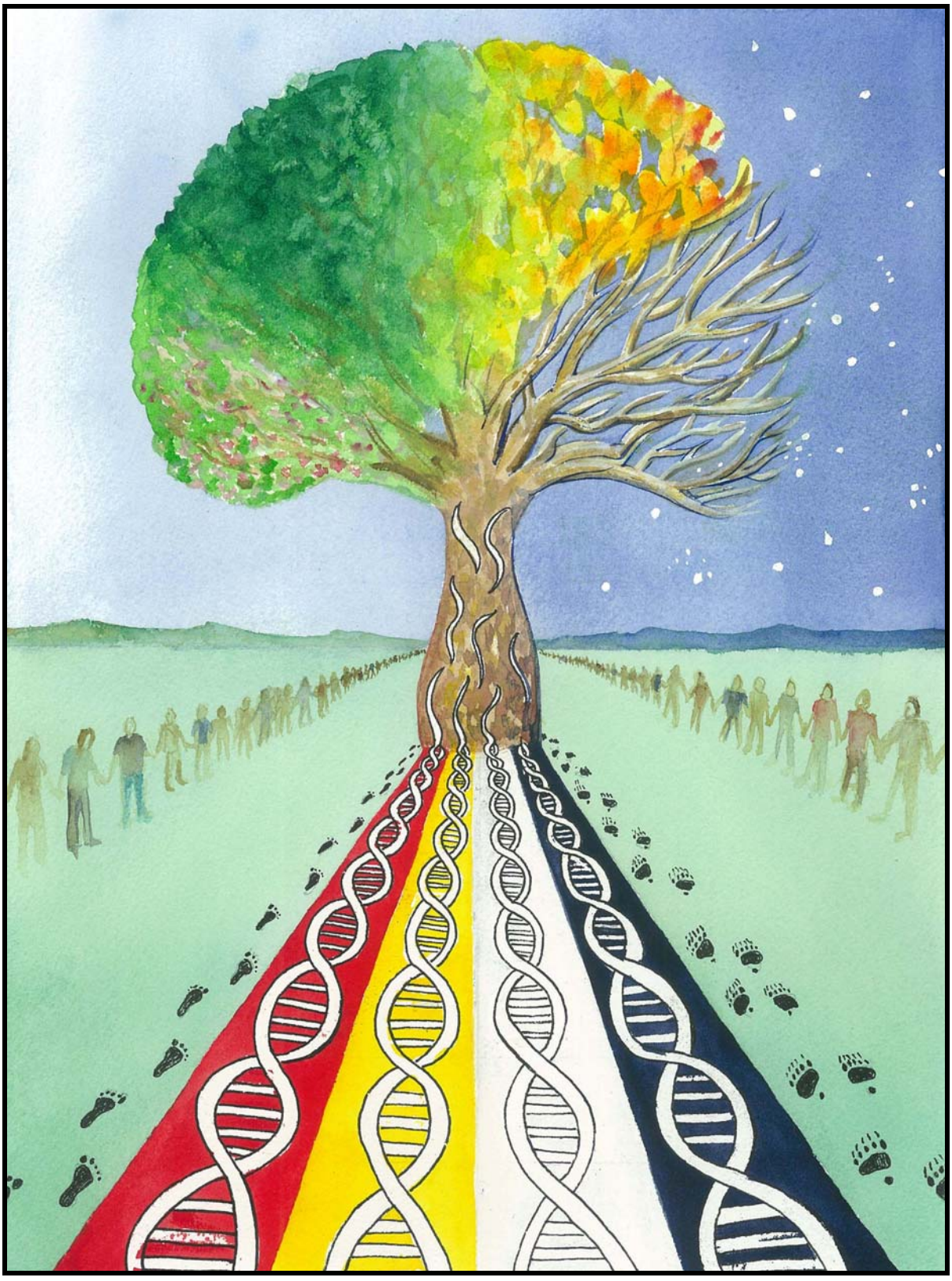
The vaccine is given in a series of 3 shots over a 6-month period. The second and third dose should be given 2 and 6 months after the first dose. No serious side effects have been reported. The most common side effect is a brief soreness at the injection site.

Women who have the HPV vaccine still need to have recommended Pap smears because the vaccine only provides protection for the 4 most common types of HPV that cause the majority of cervical cancers.

It is important to talk with your health care provider and learn more about this vaccine. You can also learn more on the Center for Disease Control (CDC), American Cancer Society (ACS) and National Cancer Society (NCI) websites.

Talk with your health care team and community members about culturally respectful ways to share this information with the people in your community to prevent the majority of cervical cancers.

Check Your Understanding answers from page 2-16:
1)F, 2)T, 3)T, 4)T, 5)F, 6)T, 7)F, 8)T



Cancer and Our Genes

Artist Statement
Cancer and Our Genes

The tree symbolizes all of the cycles of life, infant, child-spring-new beginnings, adolescence-young adulthood, summer/ adulthood-middle age, autumn/ elder hood, winter. Within the tree trunks going down to the roots are the connections to our DNA. There are 4 roots of DNA in the 4 sacred colors which also represent different ages and times as well as directions and races. They all come together to create the tree of life.

And as dawn goes into night we travel together as one people, stretching back to ancient times. I put the lines of people standing to represent all of the collective strength and experiences within humanity as well as to represent our ability to continue and persevere through lifetimes, whether that be persevering and triumphing over disease or other obstacles.

The footprints alongside the roots of the tree, the left representing humanity and the journey through life, the right bear paw prints representing healing and quiet strength, needing to go within oneself to finding hidden strength and inner healing, it also represents the more “natural” healing an individual can access for treatment with Cancer.

Cassandra Leigh Darrough
Paiute-Shoshone
August 12, 2010

Section 3

Cancer & Our Genes

GOALS

Participants will learn about the role of genes in cancer. The importance of knowing a family cancer history is discussed. Reasons people may want, or choose not, to have gene testing will also be discussed.

OBJECTIVES

At the end of this section, each participant will be able to:

UNDERSTAND the relationship between cancer and genes

RECOGNIZE the differences among sporadic, familial, and hereditary cancers

DISCUSS why or why not people may choose to have gene testing

RECOGNIZE that cancer screening recommendations may be different for families with hereditary cancers

KNOW how to take a family cancer history

Table of Contents

Cancer & Our Genes

Check Your Understanding

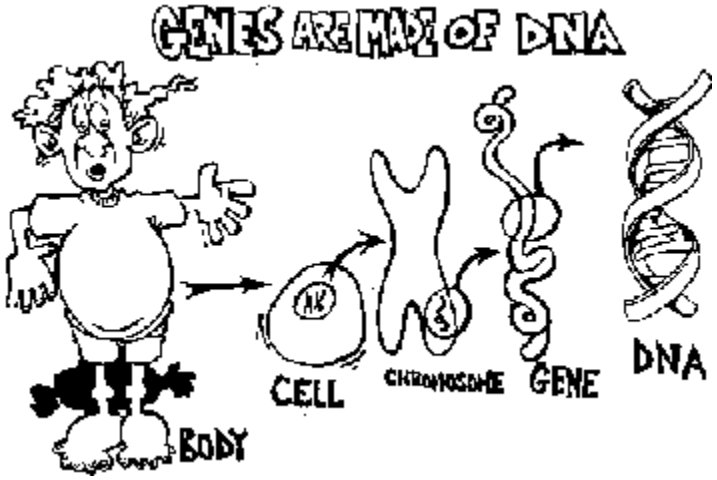
		TRUE	*FALSE*
1.	Genes carry the instructions for all of our body functions.		
2.	Cancers are the result of mutations in genes.		
3.	Most cancers are sporadic.		
4.	Hereditary cancer is very common.		
5.	The mother's cancer history is the most important.		
6.	People with hereditary cancer inherit a mutated gene from their parents.		
7.	Everybody over age 50 should have a gene test for cancer.		
8.	A negative gene test means you will not get cancer.		
9.	Inheriting a gene mutation means you will get cancer.		
10.	Counseling before and after gene testing is recommended.		

"Genetics" is the study of genes.

Genetics of Cancer

Many people have cancer in their family. Some families have more cancer than others and family members may want to know if they could get cancer too. This section will help you to talk with people about hereditary cancer.

What are genes and what do they do?



Our bodies are made up of trillions of cells. Within each cell are the 46 chromosomes that we inherit from our parents: 23 from our mother's egg and 23 from our father's sperm. Each chromosome is a double strand of DNA that contains chemical information. Genes are tiny segments of the DNA that carry instructions for making specific proteins that control cell function and growth. Each gene is one of a kind and is responsible for a very specific action. Different genes are turned on in different cells giving that cell type its special instructions.

Genes tell our body's cells how to grow, develop and function from the time of conception and continue until we die. We each have a unique set of genes inherited from our parents that give us our individual inherited traits, including physical characteristics, such as our hair color, eye color, etc.

Many factors from both within and outside our bodies can influence whether genes function properly or not. Outside factors such as exposure to tobacco, sun, chemicals, radiation, or environmental pollution can damage healthy gene function. Decreasing exposure to things that can cause harm to our cells and genes, as well as being physically active and eating in healthy ways will help our genes function normally.

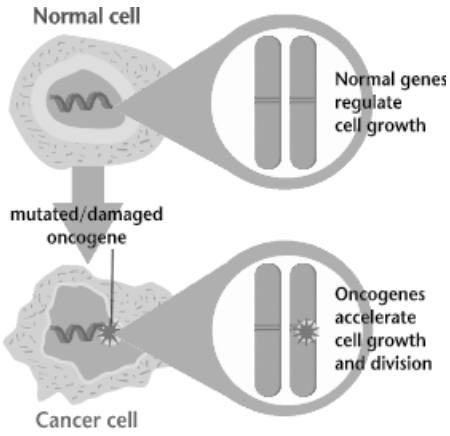
Why is cancer genetic?

All cancers are caused by changes in a person's genes. Changes in genes are called mutations. A mutation is a mistake or error in the chemical make-up of a gene. Gene mutations give cells the wrong instructions for what to do and how to function. Normally functioning cells grow and divide and know to stop growing.

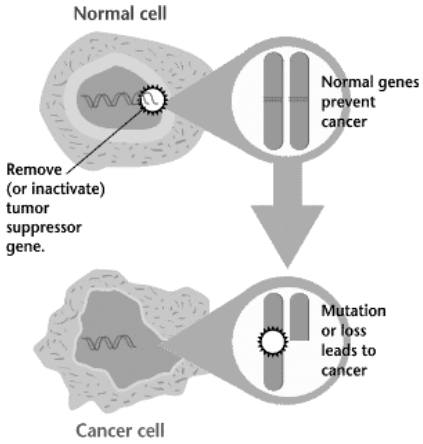
However, genes that control how cells normally grow and divide can malfunction. If this happens, the cell will divide endlessly and grow out of control. The type of gene that causes this to happen is called an **oncogene.** Genes come in pairs. If a damaged or abnormal oncogene is stronger than the healthy oncogene it will cause abnormal cell growth.

Some normal genes in cells are there to stop cells from multiplying or doubling. This prevents cancer from developing. **Tumor suppressor genes** work together in pairs to keep cancer from forming. If one isn't doing its job, the other gene will take over to keep the cell healthy. When both tumor suppressor genes are not working, cancers can form.

Oncogenes and tumor suppressor genes are only 2 of the types of genes involved in cancer.



"Oncogenes" *are damaged (mutated) genes that can cause a normal cell to become malignant or cancerous. When oncogenes are present in a cell, they tell the cell to continue to grow and divide, without stopping.*



"Tumor suppressor genes" *are normal genes that prevent cancer from developing. If both tumor suppressor genes are not working because of a mutation (damage), cancer can develop.*

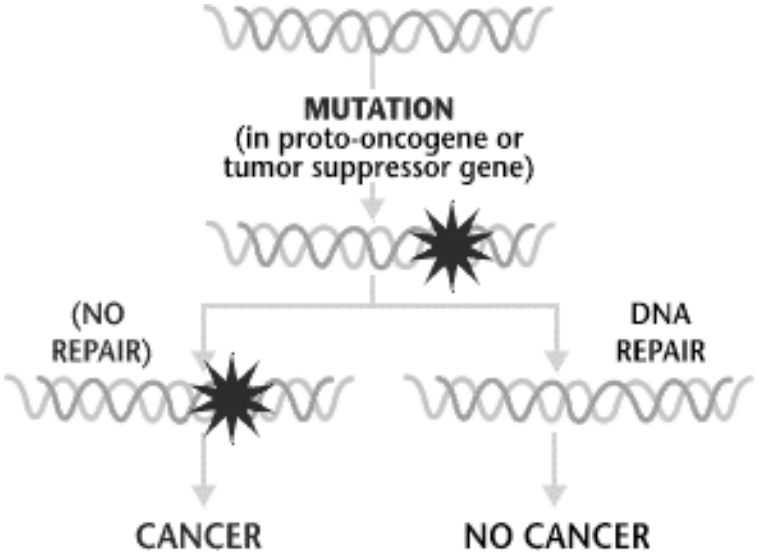
Genetics of Cancer

Oncogenes are like the accelerator pedal in a car, speeding up cell growth.

Tumor suppressor genes are like the brakes, telling the cell not to divide.

What is a mutation?

A mutation is a mistake or error in the chemical make up of a gene causing the gene to give the wrong instructions to the cell. It may be caused by damage from tobacco, alcohol, viruses, the sun, environmental pollution, or even random events within a cell. Mutations happen quite often and not all of them cause cancer. This is because we have genes in the DNA of our cells that have the job of fixing mutations. Mutations in the genes that prevent the cell from reproducing normally or that damage the DNA repair genes can cause cancer to grow. Generally, it takes many mutations and many years before a cancer starts to grow. However, if the first mutation happens in a gene that repairs or prevents mutations, then other mutations can happen quickly.

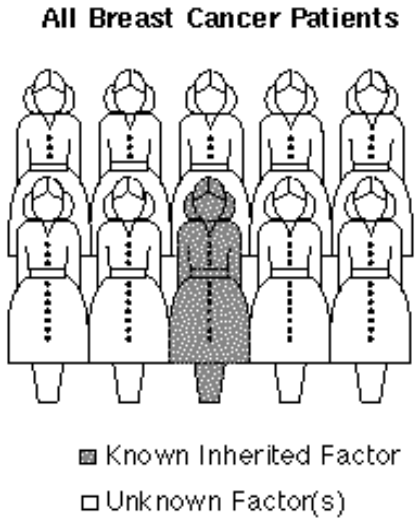


"DNA repair genes" *are special genes that protect us from cancer causing mutations. They repair errors that happen when cells copy their DNA just before they divide to make new cells. If DNA repair genes are absent or damaged, other mutations in the cell do not get repaired. If mutations in oncogenes (cancer causing genes) or tumor suppressor genes are not repaired, cancer can develop.*

Sporadic, Familial, & Hereditary Cancer

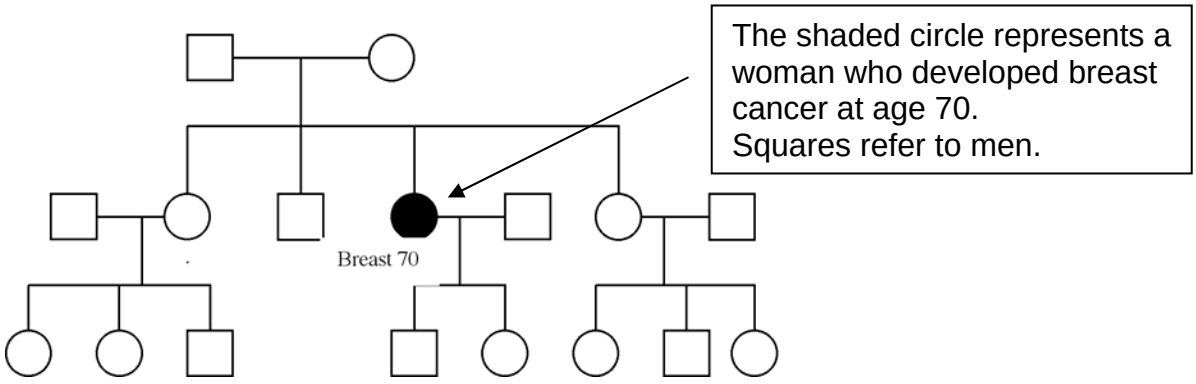
What is sporadic cancer?

Sporadic means that something happens by chance. Most cancers are sporadic and not due to an inherited cancer-causing gene. People who have sporadic cancer did not inherit cancer-causing mutations from their parents. Instead, certain cells in their body developed mutations that led to cancer. In sporadic cancer, ***only the tumor cells have the mutation; it is not found in every cell.*** A tumor is an abnormal mass of cells. Tumors can be benign (not cancer) or malignant (cancer).



The mutation is not present in other family members and is not passed generation to generation. Sporadic cancers can be any kind of cancer, and happen more often in older people. About 9 out of 10 people with cancer have a sporadic cancer.

Most cancers are sporadic and not due to an inherited cancer-causing gene. For example, only one woman in every ten women with breast cancer has an inherited cause.

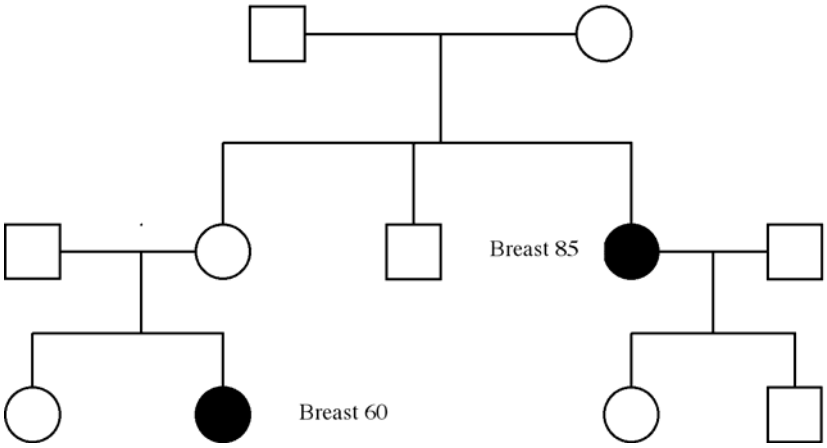


Sporadic Cancer = a single occurrence in a family
Sporadic cancers can be any kind of cancer and happen more often in older people. The cancer risk is not present in other family members and is not passed from generation to generation. Refer page 3-19 'Drawing a Family Tree'.

What is familial cancer?

Familial cancer means that cancer has happened in 2 or more blood relatives in the same family. They may be first degree relatives, such as a mother, father, daughter, son, sister, or brother, or more distant relatives such as a grandparent, aunt, uncle, niece, or nephew. There may be several different kinds of cancers within the family.

As families, we share many of our genes. We also share some of the same lifestyle characteristics like the food we eat, how much physical activity we get, our exposure to tobacco, and the environment we live in. Researchers are not sure how much of familial cancer is caused by inherited genes, and how much is caused by shared environment and by shared lifestyle. A person in a family with familial cancer has a slightly increased risk of developing cancer.



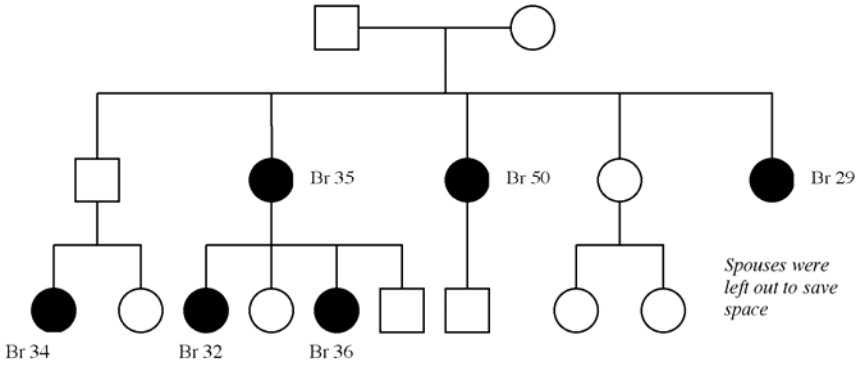
Familial Cancer

Familial cancers occur in 2 or more blood relatives. The onset of the cancers is generally later in life. In this diagram of a family tree, the 2 shaded circles represent the 2 women who developed breast cancer. One woman at age 85 and one woman at age 60. The square symbol is for men.

What is hereditary cancer?

People with hereditary cancer inherit a mutated gene from one of their parents. At time of conception, either their father or mother passes on a gene that already has a mutation and is not working. Every cell in the person's body contains the mutation. Cells of the ovaries and testes, which make eggs and sperm, contain the mutation and can pass the mutated gene to the next generation.

It generally takes more than one mutation to cause cancer. People who have inherited a mutation are one step closer to cancer than those who have not. For example, a child with an inherited mutation in a tumor suppressor gene will grow up with only one functioning tumor suppressor gene, instead of the two she or he would have normally. If the one working tumor suppressor gene gets damaged, say from tobacco use, then she or he is more likely to develop cancer and to develop it at a younger age. She or he also may pass this mutation on to her or his children. People who inherit a cancer-causing mutation are at higher risk to develop cancer, but that does not mean that **all** family members will develop cancer.



Hereditary Cancer

Hereditary cancer means there is an inherited cancer-causing mutation within a family. In this diagram of a family tree, each shaded circle represents a woman who has developed breast cancer. The number next to the circle is the age the woman developed breast cancer. The squares are symbols for men.

Hereditary cancer is not very common.
Only 5 to 10 people out of every 100 people who develop cancer, have a hereditary cancer. **Most cancers are sporadic** and not related to an inherited cancer-causing gene.

Clues to Hereditary Cancer

Here is a list of clues that could mean the cancer happened because of an inherited gene mutation. Not every family will have each of these clues.

- Several first degree relatives, such as a mother, father, son, daughter, sister, or brother, have the same type of cancer.
- The kind of cancer is an uncommon childhood cancer.
- Cancer happened in an adult at an earlier age than expected, less than age 40.
- A person developed cancer in both paired organs, both breasts developed cancer or both ovaries had cancer.
- A person developed more than one type of cancer, such as colon and breast cancer, or colon and prostate cancer.
- A man has breast cancer.
- More than one generation in a family was affected by cancer.

Where do I find the clues?

American Indian and Alaska Native peoples know the importance of preserving the past for the future. Ancestors passed on a rich heritage of hunting, fishing, food, dance, values, and GENES! The clues to hereditary cancer risk are in the family medical history. The more detailed information available, the more accurately hereditary cancer risk can be predicted. Getting a good family medical history takes time and may require some "detective" work. Here is the information you need to know:

- Who in the family has or has had cancer? Include the immediate family: mother, father, daughters, sons, sisters, brothers, grandparents, siblings, aunts, uncles, nieces, nephews, and cousins. Record three or four generations.
- Find out, if you can, exactly what kind of cancer family members had. Remember, the more details you know the better.
- If the cancer happened in paired organs, like breasts or kidneys, was it found in both breasts or both kidneys?

- Did anyone in the family have more than one kind of cancer? This information can be tricky to sort out. Cancer can spread to other parts of the body away from the primary site. When asked, people may remember that their relative had breast cancer and lung cancer, but really the breast cancer spread to the lungs. Try to find out if the first cancer spread to other organs or if it was truly a new cancer in a different organ.

- How old was the person when the cancer was found? If the relative is deceased, what was their age and cause of death?

- How old are family members who have not developed cancer?

- Having a gene with a mutation does not always mean someone will develop cancer, but that person can still pass a mutated gene to her or his children. A father who inherits a breast cancer gene from his mother has a 50% chance of passing it to his daughters or to his sons, who, in turn, can pass it on to their children. The daughters and sons who inherit the mutation will then be at a higher risk to develop breast cancer. A parent who carries a gene mutation also has a 50% chance of not passing it to her or his children. If the mutated gene is not passed on, then their child has the same cancer risk as other people without hereditary cancer in their family. Only genetic testing can determine whether a specific gene was passed on.

What is a hereditary cancer syndrome?

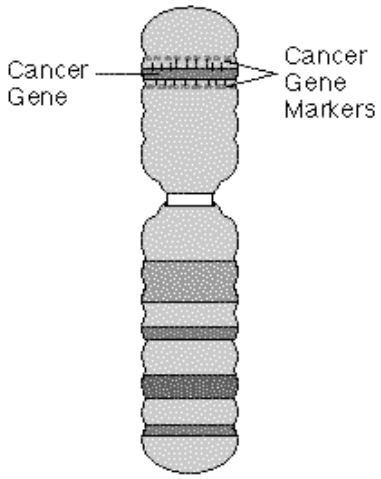
A syndrome is a set of symptoms or medical conditions that occur together. In genetics, it is a set of traits resulting from one gene. Sometimes an inherited mutated gene can cause more than one kind of cancer in a family. When this happens in a family on a regular basis, we call it a hereditary cancer syndrome, because the cancers come from the same inherited gene. Some cancer syndromes result in breast and/or ovarian cancer for a woman and prostate cancer for a man in the family. Another kind of gene causes a syndrome in which family members may have breast, thyroid, or colon cancer. Asking about ALL cancers in the family is very important. A complete family medical history is necessary to decide if a cancer is sporadic, familial, or hereditary, including a hereditary cancer syndrome. If a hereditary cancer is suspected, gene testing may be an option for the family.

Remember to ask about BOTH parents. The mother's AND father's cancer histories are important.

Gene Testing

Is gene testing for cancer available?

Researchers have identified many cancer-causing gene mutations and are continually identifying more. Gene tests are available to the public for only a few of these genes, and others are only available to research institutions. Commercially available tests for the public include those for inherited forms of breast and colon cancers.



For some inherited cancers, a special laboratory can examine the DNA (genetic material in chromosomes) for a particular gene mutation.

How is gene testing done?

A small sample of blood is sent to a special laboratory where they examine the DNA for a particular gene mutation. A positive gene test (the gene mutation is found) tells us that a person is at increased risk for cancer. It cannot tell whether or not the person will actually develop cancer.

First, they test blood from the person who has cancer to look for a gene mutation. Experts then try to decide if the mutation caused the person's cancer. The blood sample must be sent to whichever lab is an expert in testing that gene. Because some genes are very large, they may take longer to check. Results might take 3 weeks or 2-3 months, depending upon the individual gene.

If the lab finds a mutated gene, it is called a "positive result". They can then test other family members for the same mutation. If the other family members did not inherit the same gene mutation as the relative with the cancer, they have a "negative" result. A negative result does not mean they can never develop cancer. They have the same risk to develop cancer as other people in families without hereditary cancer.

If no mutation is found in the person with known cancer, this is also a "negative result". It could be that the gene mutation was not in the genes tested at the lab and a different gene has the mutation. It could be because the family has a mutation that the laboratory is not able to recognize yet (no test is currently available). When there is a "negative result", the people in the family are still at very high risk for cancer based upon their family history. The lab just didn't find the gene mutation causing that family's cancer.

Sometimes a laboratory finds a change in the gene that has not been seen before, but they aren't sure if it caused the person's cancer. This result is "uncertain" or "inconclusive", and can be very confusing and frustrating for the family. It is important for people to understand this uncertainty might happen, even though they are hoping for a clear answer. Since gene testing might not give a person a clear answer, it is important to talk about all the information so people can decide if they want the testing done.

STEPS IN GENE TESTING

Individual with cancer is tested

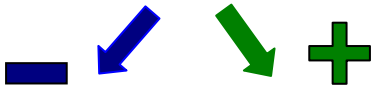
NEGATIVE FINDING

- Mutation not present.
- Mutation present but testing was not able to find.
- Gene testing of other family members not useful.

POSITIVE FINDING

(mutation present)

Other family members can be tested.



NEGATIVE

Hereditary cancer risk not increased.

POSITIVE

Hereditary cancer risk increased.

Who should consider gene testing?

Gene testing might be useful for someone who appears to have a hereditary cancer, and for individuals in a family that has a family medical history consistent with a hereditary cancer. Consider gene testing when the family has:

- Cancer in multiple generations.
- Multiple persons with the same cancer.
- Unusually young age of onset for a specific cancer, less than 40.
- Cancers in both paired organs.
- Cancers in two major body parts.

It is important for a person to carefully consider all the reasons why and why not gene testing might be helpful before having a gene test.

Is gene testing helpful?

Some people say yes, that it is a relief to know if they have the mutation or not. If they are truly negative, they can have cancer-screening tests done on the schedule recommended for the general population. If they know they are positive, they may have more checkups, or decide to use medicines or surgery to help prevent the inherited cancer from developing. It is important to remember a positive test result does not mean cancer will develop for sure, and it does not tell you at what age cancer might develop.

Gene testing may help a person to:

- Make health care choices, such as more frequent screening exams, medicines to help prevent cancer, or surgery to remove organs that might develop cancer.
- Find out if she or he has or does not have a mutated gene.
- Understand her or his risk of developing cancer.
- Give family members useful information.
- Change her or his lifestyle to help prevent cancer such as increasing physical activity, eating a healthy diet, and stopping tobacco use.

A negative test result could make someone think they have no chance of developing cancer. They might think they do not need recommended health care screening exams, and this could be very harmful. It is important for people to understand that even though they had a negative gene test, they still have the same risk of developing cancer as the general population.

What are reasons people choose not to have gene testing?

There are many reasons why people choose to have or not have gene testing done. It is a very personal decision that varies from family to family and among people within a family at risk.

A person may not want to do gene testing because:

- They do not want to know if they have a higher risk of developing cancer.
- Gene testing is very expensive, and it is not always paid for by health care insurance.
- Currently, if a mutated gene is found it cannot be fixed.
- They may worry they have passed a cancer gene on to their children.
- They may become angry if they have a mutated gene and someone else in the family does not have the mutated gene. Other family members may feel guilty if they do not have the mutated gene.
- It can be frustrating if a gene test result is uncertain.
- They may have concerns about discrimination in the workplace or eligibility for health care insurance and life insurance.
- A positive test result in one family member affects other family members even if they decide not to be tested.

Each person must decide for herself or himself. To make this decision, a person needs information about gene testing and what it can and cannot offer. It is recommended that families and individuals seek assistance with this decision-making process from their health care provider and/or a genetic counselor. Some people learn more about gene testing and decide not to do it. Other people might want to have gene testing at first, but then change their minds, and do not want to know their test results.

Who are genetic counselors and what do they do?

Genetic counselors are people trained in the scientific, medical, and emotional aspects of inherited diseases. Cancer genetic counselors specialize in counseling and educating individuals and families with cancer or who are at risk for hereditary cancer.

Genetic counselors help families to collect and interpret their family medical history. They assess the likelihood of hereditary cancer and make recommendations about gene testing. They explore the medical, emotional, and financial implications of cancer risk and gene testing.

Genetic counseling is recommended before and after gene testing. After a discussion with the genetic counselor and time to think, the individual makes the personal choice whether to have gene testing or not. The counselor can arrange gene testing if it is available, and explain the possibility of negative, positive or uncertain results. A counselor can help people cope with their feelings about cancer and testing and medical issues. They can also suggest ways for a person to decrease her or his risk of developing cancer by making healthy lifestyle choices and having recommended screening exams.

Reducing the Risk of Cancer

For people at high risk for hereditary cancer, depending upon their unique situation, there is a variety of screening and risk reduction options they should discuss with their health care provider:

- cancer screening exams
- diet, exercise, and lifestyle activities
- preventive surgeries
- cancer prevention medications

Finding and treating cancer early saves lives! Having a hereditary risk for cancer is all the more reason to have recommended screening exams for early detection. People at an increased risk for developing cancer may need to be screened more frequently or begin at a younger age.

Individuals at high hereditary risk for developing cancer may consider preventive surgery to remove the specific organ. Some women at high risk for hereditary breast or ovarian cancer may choose to have surgery to remove both breasts, or to have their ovaries taken out, before cancer has a chance to develop. Some people at high risk for colon cancer may choose to have their entire colon removed. These preventive surgeries will reduce the person's risk for cancer, but it is not 100% for sure the person will not develop cancer.

Remember --- A person's risk for developing cancer can be higher because of inherited genes, but it does not mean that he or she will develop cancer. All people can make lifestyle choices to help prevent cancer and live a healthier life.

Check Your Understanding answers: 1)T, 2)T, 3)T, 4)F, 5)F, 6)T, 7)F, 8)F, 9)F, 10)T

Family History Questions for Cancer

As part of a family medical history, ask:

Has anyone in your immediate family related by blood (mother, father, brother, sister, son, or daughter) had cancer?
Yes or No

If Yes, the answers to the following questions help to identify people that may be at risk for a hereditary cancer.

To learn more, Ask ...

1. In your mother's family or father's family, including yourself, have two people related by blood had the same type of cancer?
   Yes or No
2. Including yourself, has anyone in your family had cancer in matching organs (for example, cancer in both breasts, ovaries, kidney, eyes)?
   Yes or No
3. Including yourself, has anyone in your family had cancer at age 40 or younger?
   Yes or No
4. Including yourself, has anyone in your family had two different cancers that began in two different organs? Examples would be breast and ovarian cancer in the same person or colon and kidney in the same person.
   Yes or No

If the answer is "yes" to any of the questions 1 - 4, talk to your health care provider about getting a more complete family cancer history.

Drawing a Family Tree

A family tree or a family pedigree is a map of a family medical history. It is made using the information from family members, medical records, and death certificates. When you make a family tree, you can include all medical problems or focus on a specific medical or health concern such as cancer, heart disease, or diabetes. In this section, we are learning about cancer within a family.

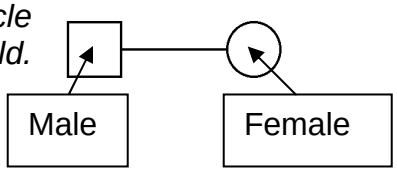
Start with a blank family pedigree (see page 3-22) and begin to fill in family members and whether or not they have cancer. If they have or had cancer include what type of cancer and how old they were when they were diagnosed. Include family members who have died, their cause of death and age.

Common symbols are:

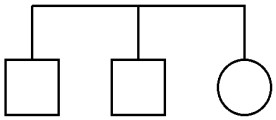
Squares mean males.

Circles mean females.

A square connected to a circle by a single line means they had a child.



Squares and circles hanging on a line mean brothers and sisters (siblings). (In this example there are two brothers and one sister.) Put the oldest at the left across to the youngest at the right.



Filled in squares and circles mean those family members have or had cancer. Put what kind of cancer(s) and how old they were when they were diagnosed with cancer.

A line through a square or circle means that family member died.

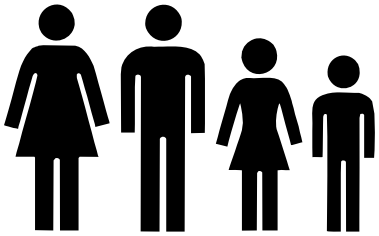
How to Draw a Family Tree or Family Pedigree

Clues to Hereditary Cancer in this Family

Refer to 3-21

- Breast cancer is present in 3 generations without skipping a generation.
- Breast cancer occurs at a younger age than usual, less than age 40.
- Ovarian cancer is present in 2 generations without skipping a generation.
- Ovarian cancer occurs at a younger age than usual less than age 40.
- Breast and ovarian cancers occur in one individual.

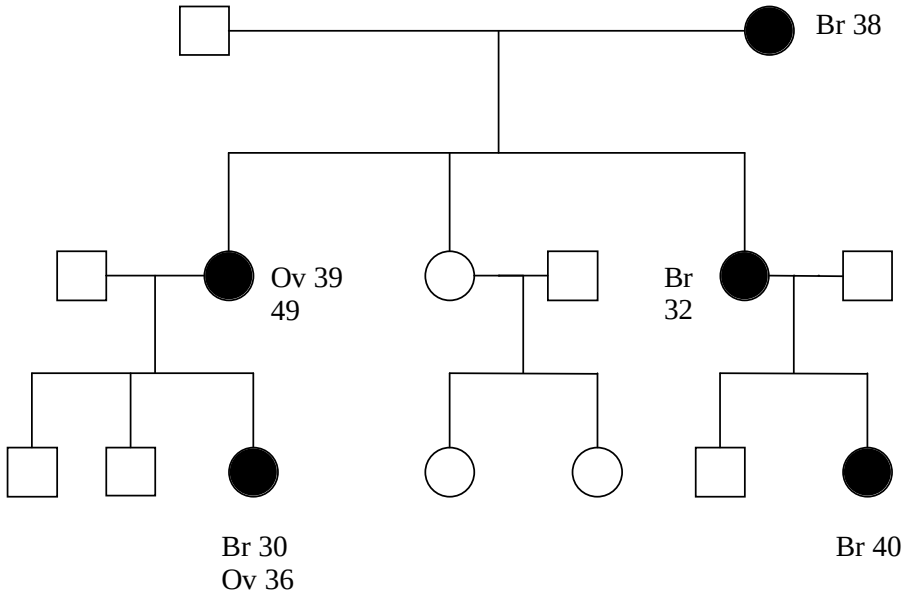
For example, a family member was tested and found to have a gene mutation for breast cancer. Other family members may choose to be tested to determine their hereditary risk for developing cancer.



Cancer & Our Genes

Example of a Family Pedigree

This family tree has clues that may mean there is a mutated gene causing hereditary cancer. What are the clues?



= male

= female

= married

or = affected with cancer

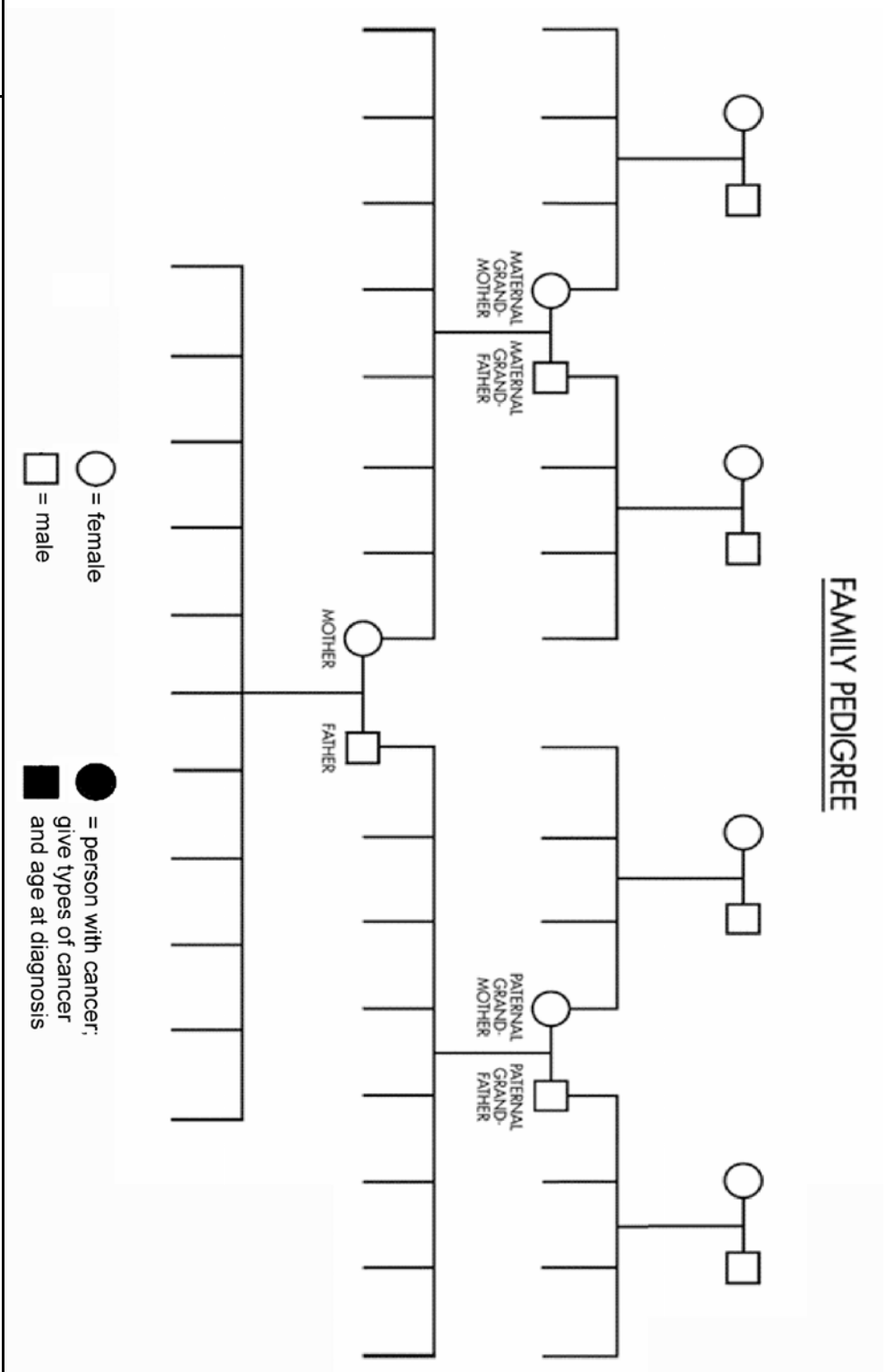
= siblings (brother and sister)

Br = breast cancer Ov = ovarian cancer

Numbers = age at onset of cancer

Cancer & Our Genes

Example of a Family Pedigree



CHR Dancer

Artist Statement
CHR Dancer

For years Native people have used dance as a form of prayer and as a way to celebrate life. There is a movement among Native America to raise awareness of cancer. It began in 1993, with the Pink Shawl Project, to raise awareness of Breast cancer. Since then, it has been adapted by the Native People's Circle of Hope to raise awareness of other types of cancer.

I wanted to portray my CHR dancer as a woman we could all picture ourselves knowing. She could be a friend or a mother, a sister or an aunt who through her dance is honoring her people. With her bright yellow shawl she honors the spirit of Hope, while the many colors of her ribbon fringe represent the different types of cancer.

Cassandra Leigh Darrough
Paiute-Shoshone
April 19, 2008

Section 4

Understanding Cancer Basics

GOALS

Participants will learn how a cancer diagnosis is made. Emotional responses to a cancer diagnosis and ways to provide support will be discussed. Participants will also learn common medical words used when describing cancer, a cancer diagnosis, and cancer treatment.

OBJECTIVES

At the end of this section, each participant will be able to:

STATE how a cancer diagnosis is made

UNDERSTAND the importance of cancer site, grade, and stage

DISCUSS the emotional effects of a cancer diagnosis

IDENTIFY ways to provide comfort and support for people diagnosed with cancer and their caregivers

Think about what you can do or say or how to be to support someone who has been diagnosed with cancer. Remember he or she is not cancer itself but a person living with the disease called cancer.

What traditional stories provide hope and courage for a person to live well along their journey of being diagnosed with cancer?

Table of Contents

Cancer Basics

Check Your Understanding

		TRUE	*FALSE*
1.	Cancer is one disease.		
2.	Tumors can be benign or malignant.		
3.	Cancer cells rob nutrients from nearby tissues and destroy normal cells or push them out of the way.		
4.	Cancer cells grow without control or order.		
5.	A benign tumor means you have cancer.		
6.	Stage is a medical term used to describe how far a cancer has spread.		
7.	If someone has breast cancer and it spreads to the lungs, the person then has breast cancer and lung cancer.		
8.	A doctor can tell if a person has cancer by looking at an x-ray.		
9.	Malignant tumors have the ability to spread to other parts of the body.		
10.	A cancer diagnosis does not mean you are going to die from cancer.		
11.	Cancer can only be definitely diagnosed by looking at a sample of tissue under a microscope.		
12.	Cancer can occur anywhere in the body.		

Through sharing our stories and combining our knowledge, we can understand the disease of cancer.

Understanding Cancer Basics

Welcome, we are glad to join with you in learning about cancer. Many of us are concerned about cancer. When people hear the word 'cancer' a lot of thoughts and feelings come to mind. We may know family, friends or people in our communities who have experienced cancer, and we are aware of some of the ways in which a diagnosis of cancer may affect their lives and our lives. We wonder how to make meaning of the experience of cancer.

Through sharing our stories and combining our wisdom and knowledge, we can learn ways to understand cancer. When cancer is found and treated early, cure or remission is possible. **In the words of a cancer survivor, "A cancer diagnosis is NOT a death sentence."** Today many people who have been diagnosed and treated for cancer are living well. Within the story of cancer we may discover new meaning, changing the way we embrace our life journey.

What is cancer?

Cancer is not just one disease, but a group of over 100 different diseases. Cancer occurs when cells divide and form more cells without control or order. This abnormal cell growth creates a mass of new tissue. Every part of the body is made of cells. Normal cells divide to produce more cells at the rate the body needs them. The many, many cells in our body must divide numerous times a day. This process is carefully controlled by our genes.

If cells keep dividing when new cells are not needed, a mass forms. This mass of tissue is called a growth or **tumor**. It can be benign or malignant. **Benign tumors** are not cancer - they do not spread to other parts of the body and are not usually a threat to life. They may be removed because of their size or if they are bothering a person. Benign tumors usually do not grow back after they are removed.

Malignant tumors are cancer cells which divide without control or order. Cancer cells take nutrients from nearby tissue and destroy normal cells or push them out of the way. Cancer cells can also enter the blood stream and/or lymph system and spread to other parts of the body. This spread of cancer cells to other parts of the body is called **metastasis**.

How is a cancer diagnosis made?

A cancer diagnosis can only be made by looking at tissue from a **biopsy** under a microscope. A biopsy is the removal of a small sample of tissue. Under a microscope, cancer cells look different than normal cells in size, shape, and how they are arranged.

Cancer is diagnosed by taking a tissue sample, called a biopsy, and looking at those cells under a microscope.

When cancer is found and treated early, cure or remission is possible.

Primary Cancer Site

Where did the cancer start?

Most cancers are identified by the organ in which they first begin to grow. The place where the cancer first starts to grow is called the **primary tumor site** or **primary site**. When cancer spreads or metastasizes, the new tumor has the same type of cells as the original (primary) tumor. If lung cancer spreads to the liver, the lung cancer is said to have metastasized to the liver, and the tumor in the liver is called metastatic lung cancer. The person's diagnosis is lung cancer with metastasis to the liver (lung cancer with liver 'mets').The person does not have lung cancer and liver cancer.

What type of cancer is it?

There are over 100 different types of cancer. In addition to the primary organ site, cancers are described by the types of cells that become malignant or cancer. It is important to know the stage, grade, and type of cancer to determine the best treatment.

There are six main groups:

Carcinomas are cancers that begin in the epithelium, the body's skin and in tissues that line the internal organs. Eighty to 90% of all cancers are carcinomas.

Sarcomas are cancers that start to grow in bone, fat, muscle, nerve, joint, blood vessel, or deep skin tissues. Sarcomas are given different names depending upon the type of tissue where they begin to grow. For example, osteosarcoma starts in the bone, chondrosarcoma begins in the cartilage, leiomyosarcoma begins in the smooth muscle and liposarcomas are cancer tumors of the fat tissue. Kaposi sarcoma may develop in people who are infected with HIV and is a cancer formed by cells similar to those lining blood or lymph vessels.

Mixed Tumors are cancers made of sarcoma and carcinoma cells.

Lymphomas are cancers that start in the lymph nodes or lymph tissue.

Leukemias are cancers of the white blood cells produced in the blood-forming tissues, mainly the bone marrow, lymph nodes, and spleen.

Myelomas are cancers that start in the plasma cells made in the bone marrow.

There are over 100 different types of cancer.

Remember…

cancer is just a word used to describe a disease,

it is not the person.

Tumor Grade

How aggressive is the cancer?

Tumor grade describes how closely the cancer cells look like normal cells of the same type. Tumor cells are well differentiated when they look and function similarly to normal cells of the same type. Poorly differentiated and undifferentiated tumor cells look abnormal and disorganized. A specially trained doctor, called a pathologist, uses the numbers 1 to 4 to grade a tumor.

The standard tumor grades are:

Cancer cells look different than normal cells in size, shape, and arrangement.

GRADE 1 - Well differentiated

GRADE 2 - Moderately well differentiated

GRADE 3 - Poorly differentiated

GRADE 4 - Undifferentiated

The grade (or differentiation) of a tumor refers to how fast the cells are growing or how aggressive the tumor is. **Low grade tumors** have well differentiated cells, are slow growing and less aggressive. **High grade tumors** have poorly differentiated cells, are fast growing and more aggressive. Tumor grade also helps determine **prognosis**, the probable outcome or chance of recovery from the cancer.

A breast cancer is “poorly differentiated” if the tissue does not look like normal breast tissue. It grows faster and is more difficult to treat than a breast cancer that is “well differentiated”, one that looks like normal breast tissue. Information about tumor grade helps health care providers plan the best treatment.

Stage of Cancer

How far has the cancer spread?

The stage of the disease describes how far the cancer has spread beyond the organ in which it first started to grow. Stage is determined using selected tests and procedures that may include: surgery, various imaging techniques, blood tests, and biopsies.

Four common stages of cancer are:

IN-SITU - Cancer cells are found in one tissue area and have not invaded normal surrounding tissue.

LOCAL - Cancer is found only in the organ where it started to grow.

REGIONAL - Cancer has spread to the surrounding tissues or lymph nodes.

DISTANT - Cancer has spread to other organs and systems of the body.

A cancer in-situ may be completely removed with surgery. In this case the patient is cured and needs no further cancer treatment. Depending upon the type of cancer, in-situ may require surgery, radiation treatment or hormonal treatment. A cancer with distant metastases is more advanced and more difficult to treat.

Another system of staging uses the words Tumor (T), Nodes (N), and Metastasis (M) with a number score. The stage of each cancer is very specific to each type of cancer.

TUMOR (T) - the size of the cancer growth and how far it has spread into nearby tissue.

NODES (N) - how many lymph nodes in the region of the cancer tumor have cancer cells in them.

METASTASIS (M) - Cancer is found in distant parts of the body far from the primary site of origin.

As information about a person's cancer is gathered, a number score is noted for T, N, and M. Zero (0) means no evidence of cancer, while numbers increasing in size (1-4) mean larger or more disease. An "X" indicates the exact status is not known.

Staging is an important part of making an accurate diagnosis and developing the best treatment plan.

Knowing the stage of cancer helps medical doctors to develop the best treatment plan.

Medical manuals are available that describe what the TNM numbers mean for the different kinds of cancer. Because there are many TNM combinations, they are grouped into four stages (I-IV). Stage 1 cancer means the cancer has been diagnosed early and with treatment the person has a good prognosis. Stage 4 or Stage IV means the cancer has spread to another part of the body.

Stage 1 cancer means the cancer has been diagnosed early and there is a good prognosis.

Examples using the TNM system to stage colon cancer:

A 51 year old male has colon cancer. The tumor has not invaded the layer of tissue just below the lining of the colon (T1), no lymph nodes show cancer cells (N0) and no distant metastases are found (M0). He has Stage I colon cancer.

A 62 year old female has colon cancer. The tumor has invaded deeply into the tissues of the colon (T3). Three regional lymph nodes are positive for cancer cells (N1). There is no evidence of distant metastasis (M0). She has Stage III colon cancer.

A 70 year old male has colon cancer that has spread or metastasized to his liver. Cancer with metastasis (spread) to another part of the body is Stage IV. The tumor may be any size, with any number of lymph nodes: Any T (tumor), Any N (nodes), combined with M1 (metastasis) is Stage IV.

Providing Comfort and Support

You may know someone who has been diagnosed with cancer, or you may have watched a movie and heard how people responded to their diagnosis of cancer.

People respond to a cancer diagnosis in many ways. Shock, confusion, anger, grief, sadness, disappointment, despair, disbelief, denial, and fear are all common reactions. Each of us has our own personal way of responding to a situation.

How can we help?

Although cancer is an individual diagnosis, no one needs to feel like they have to experience cancer alone. It takes a lot of heart and courage to cope with cancer. Cancer not only affects the person with cancer but also family and friends.

Sometimes people refer to cancer as the 'Big C' or the 'C word'. Remember there are 3 simple letters at the beginning of the word cancer…CAN. Together, we **can** make a difference. Think about other supportive "C" words: comfort, cope, caring, compassion, communication, community, cuddle, chocolate, chuckle, corazon (Spanish for heart), courage, connections and Community Health Representatives to name a few.

Remember, you are not alone. You are part of a caring community of family and friends.

Things you can do when someone you know has cancer:

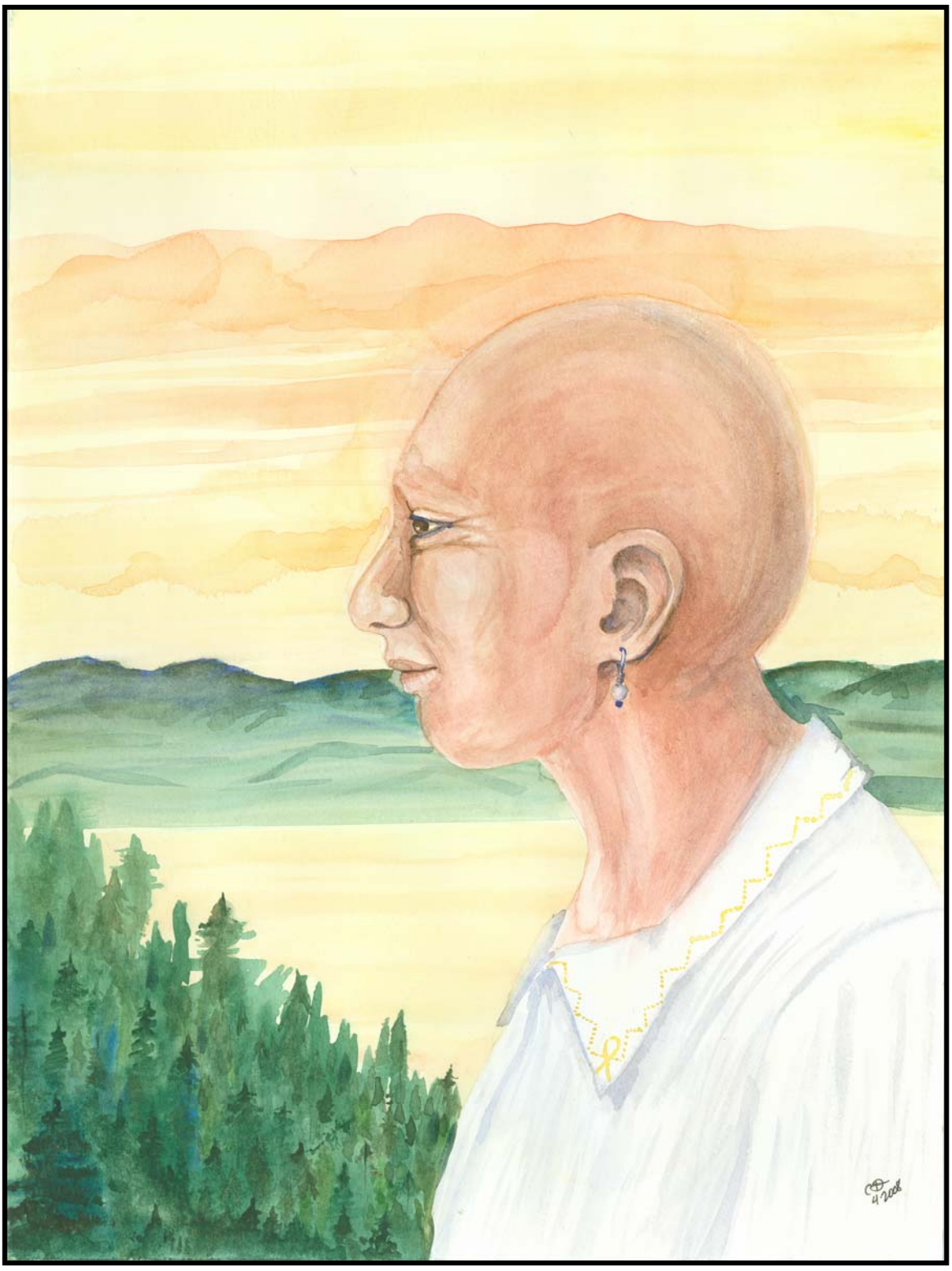
- Talk story. Focus on the person, not the disease.
- Share feelings, laughter and tears.
- Share silence, just be present. We are human beings; we don't always have to be human doings.
- Stay connected with the person.
- Bring a meal.
- Go with the person to their medical appointments if they would like you to go.
- Run errands. Shop for food.
- Spend time with their kids and grandkids.
- Sing together, make music.
- Pray together.
- Tell or read stories of hope and courage.
- Play games or cards.
- Watch funny movies together; laughter is healing medicine.
- Go for a walk together and enjoy nature.

When people were asked, "What's important in living with cancer?"

- 84% said appropriate medical care
- 75% said emotional support within the family
- 73% said having hope

It is clear from these comments that emotional and social support are as essential as medical care! (What Can We Learn from Cancer, by Mark Clements, Parade Magazine, February 6, 2000. Results are based on 1094 responses from a national population sample of men and women 18 years or older.)

Check Your Understanding answers from page 4-3:
1)F, 2)T, 3)T, 4)T, 5)F, 6)T, 7)F, 8)F, 9)T, 10)T, 11)T, 12)T



Being Well

Artist Statement
Being Well

I used warm colors in this painting to convey a sense of peace. I then placed her in an environment that shows her connection to the earth and the important part it plays in healing of the whole self. She knows she is surrounded by the natural world and its comfort. Her expression is one of strength and she has no fear. Unwavering in her faith and accepting of what has been placed in her path, she is trusting life.

She even has a hint of a smile, even though she is showing signs of side effects of treatment. It has not shaken or taken away her identity. Instead it has affirmed her life and given her the gift of new perspective and appreciation.

Cassandra Leigh Darrough
Paiute-Shoshone
April 19, 2008

Section 5

Cancer Treatments: What to Expect

GOALS

Participants will gain a basic understanding of cancer treatments, common side effects of treatment, and comfort measures.

OBJECTIVES

At the end of this section, each participant will be able to:

EXPLAIN why a person diagnosed with cancer may need several types of cancer treatment

KNOW what to expect when having cancer treatment

UNDERSTAND that people living with cancer experience a variety of physical and emotional stresses both during and after their cancer treatment and that healing from these stresses may take a long time

In your community, what are traditional ways of healing to support a person's cancer treatment journey?

If someone in your community is being treated for cancer, how can you as a CHR support their healing journey?

Possibilities include:

- Call or visit to say hello and let the person know they are not alone.
- Bring a meal.
- Share cancer resources.

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Cancer Treatments: What to Expect

Check Your Understanding

		TRUE	*FALSE*
1.	Cancer treatment is most effective when the cancer has not spread to other parts of the body.		
2.	When a person's hair falls out from cancer treatment, it never grows back.		
3.	Remission is when there are no more cancer cells in a person's body.		
4.	Cancer treatment can include one or more of the following: chemotherapy, radiation , and surgery.		
5.	If a person's cancer recurs it can be treated again.		
6.	If cancer is found early, it is more easily and effectively treated.		
7.	Surgery is often the first step in treating cancer.		
8.	Chemotherapy is a systemic treatment.		
9.	Radiation therapy is a systemic treatment.		
10.	There is no need to worry if a person receiving chemotherapy has a temperature of 100.5 degrees or higher.		

Understanding Cancer Treatments

After a diagnosis of cancer is made, the work of healing begins. Cancer treatment can include many different ways of healing to support a person's physical, emotional, and spiritual journey of wellness. What traditional healing ways are used in your community? How will they support a person's cancer treatment journey? Meditation practices, healing ceremonies, or prayer may provide spiritual strength and comfort. Laughter, music, and art can also support a person's holistic healing journey.

Cancer treatment includes many different ways of healing to support a person's physical, emotional, and spiritual journey of wellness.

In developing the best treatment plan for each person, the health care provider considers:

- type of cancer
- extent or stage of the disease when first diagnosed
- person's age
- overall health
- response to treatment

Some cancers are easier to treat than others and the person may be considered cured as soon as the malignant or cancer tumor is surgically removed. Some types of cancer are easier to find and diagnose early. Cancers affecting internal organs, such as the lungs or stomach, are not as easy to diagnose. These cancers often are not found until the disease is more advanced and more difficult to treat. When the cancer is found early, while in its site of origin (in-situ), treatment is more effective.

What is a cure?

The word **cure** means the person's cancer is not likely to reappear. Time periods of one year, five years, and ten years describe cure rates for certain types of cancer. Because cancer may reappear, some health care providers prefer to use the phrase, "five-year survival without clinical evidence of disease" instead of the word cure.

Each person's treatment is individualized to best support that person's wellness.

What is remission?

Remission means that all signs and symptoms of the disease are gone, although cancer cells may remain hidden in the body. Remission is not the same as cure. Remission may be temporary and the cancer may reappear. Remission may be described as a

- **Complete Remission (C.R.)** or **No Evidence of Disease (N.E.D.) -** where there are no signs or symptoms of disease
- **Partial Remission (P.R.) -** when the tumor has responded partially to treatment by shrinking or decreasing in size
- **Stable Disease** -when the cancer, as a result of treatment, does not appear to be spreading or growing

Types of Cancer Treatments

Treatment methods may be used alone or in combination, depending upon the type of cancer, the extent or stage of the cancer, and the age and health of the person. A combination of different treatments is used because each cancer treatment attacks cancer cells and their growth cycle in a different way. The use of more than one type of cancer treatment is called combined modality therapy or treatment (C.M.T.). Other common words are adjuvant therapy or adjuvant treatment. Adjuvant means to help or assist. Adjuvant therapies help treat cancer and prevent cancer recurrence. Different types of treatments are used in combination to kill as many cancer cells as possible. Surgery and radiation are local treatments, removing or attacking the cancer cells at the primary site. Chemotherapy is a systemic treatment attacking cancer cells throughout the body.

Cancer treatments are designed to kill as many cancer cells as possible. Unfortunately, it is difficult to limit the effects of current treatment to the cancer cells alone, and often healthy cells are damaged. This is why people need time to heal and regain strength between treatments.

If cancer comes back and is detected, a treatment plan to provide the best possible outcome will be discussed. Together the patient and their health care provider choose the best plan of care. All patients have the right to have medical information shared with them in ways they can understand. This may include having an interpreter translate information or asking the health care provider to explain medical words in easy to understand English. It can be helpful to have someone go with the patient to their appointments to support patients in talking with their health care provider and take notes about the person's cancer and treatment plan. With the patient's permission, CHRs can encourage family members or friends to go to appointments or treatments with the patient.

Strong, healthy, well-nourished people often have few side effects and, in many cases, continue their normal daily activities during cancer treatment. Remember that while the side effects of cancer treatment may be unpleasant or uncomfortable, most are temporary and go away after treatment is completed.

One common side effect for most treatments is loss of appetite. It can be a challenge to maintain a healthy diet during cancer treatment. Getting adequate calories and nutrition is essential in helping the body heal. People who are well-nourished before cancer treatment and continue to eat a well balanced diet throughout treatment are less likely to experience severe side effects.

If the person does have side effects from their cancer treatment it is important for the person to tell their provider. There are many different ways to decrease the side effects of cancer treatment.

CHRs can help patients to understand the importance of asking questions about their cancer treatment plan and recognizing and reporting any cancer treatment side effects as explained by their health care provider.

Cancer Treatments: *What to Expect*

Clinical trials help health care providers determine what cancer treatment options are most effective.

What is the goal of treatment?

The goal of cancer treatment varies depending upon the type and the stage of cancer and the overall health of the person. After a complete evaluation and determination of the specific cancer and stage, the patient, their family, and their health care provider will discuss the goal of her or his treatment plan. It is important for the person to understand their treatment plan and goal.

If the cancer is found early, cure may be the goal. Other times, remission may be the goal of treatment. **Complete remission (C.R.)** or **no evidence of disease (N.E.D.)** mean that all signs and symptoms of the disease are gone, but there is a chance the cancer may return. If C.R. is not possible, the goal of treatment may be **partial remission (P.R.)** to decrease or shrink the cancer. For some people the goal may be **stable disease**, to keep the cancer from spreading or growing. If there is no treatment available to prevent further spreading of the cancer, palliation may be the primary goal of treatment. **Palliative care** focuses on comfort and providing the best quality of life. Many people now live with cancer as a chronic disease.

What are clinical trials?

Clinical trials are research studies that evaluate promising new treatment options. The purpose of these research studies is to find better ways to prevent, detect, diagnose, and treat cancer and to improve cancer patients' quality of life. Clinical trials offer important treatment options for many people with cancer and may be offered as part of a person's treatment plan for cancer. People who participate in clinical trials may have the first opportunity to benefit from a new treatment. They also make an important contribution to the advancement of knowledge to fight cancer. People with cancer may volunteer to be part of a clinical trial. To learn more about clinical trials in your area you can contact the Cancer Information Service at 1 800-4CANCER or ask your health care provider.

There are 5 phases of clinical trials.

PHASE 1: This is the first phase of a clinical trial and the purpose is to determine a safe dose for humans. The people who participate in phase 1 clinical trials are real heroes in choosing to devote the rest of their lives to improve the quality of life for future cancer patients.
PHASE 2: Research that combines a current standard therapy with a new drug.
PHASE 3: Research trials that compare a new drug to a current standard therapy.
PHASE 4: Research trials to determine how effective a drug is when treating cancer.
PHASE 5: Clinical trials concerned with the effects of treatment on a person's quality of life.

Surgery

Surgery removes a cancer tumor by cutting it out. Healthy tissue surrounding the cancer will also be removed to eliminate any cancer cells that may be hidden there. Surgery is often the first step in treating cancer. It is most effective when the cancer is still confined to its original site and can be completely removed.

Types of specialized surgery include:

- **RADICAL SURGERY:** the removal of the tumor as well as tissues, organs, and lymph glands near the tumor site that may contain cancer cells.
- **PALLIATIVE SURGERY:** surgery to relieve pain, to control the spread of the cancer, or to provide comfort care. Nerves may also be cut to relieve pain.
- **PREVENTIVE SURGERY:** the removal of a benign (noncancerous) growth, which might become malignant if left untreated. It is often used for precancerous growths such as moles on the skin or polyps in the colon.

Side Effects of Surgery

The side effects of surgery and a person's recovery time depend upon the location of the tumor, the type of operation, and the person's general health.

Hormone Therapy

Some types of cancer, including most breast and prostate cancers depend upon hormones to grow. Hormones are natural substances produced in the body. Sometimes, people have surgery to remove organs such as the ovaries or testicles that make the hormones. In other cases, medicines are used to stop hormone production or change the way hormones work. Like chemotherapy, hormone therapy is a systemic treatment; it affects cells throughout the body.

Side Effects of Hormone Therapy

Hormone therapy may cause nausea, vomiting, swelling, weight gain, and hot flashes. In women, hormone therapy may cause menstrual periods to be interrupted or ended, vaginal dryness, and loss of fertility. Common hormone therapy medications for women include: tamoxifen®, arimidex® and lupron®. In men, hormone therapy may cause impotence, loss of sexual desire, or loss of fertility. These changes may be temporary, long lasting, or permanent. Common hormone therapy medications for men include: lupron®, zoladex®, and eulexin®.

Surgery removes a tumor by cutting it out.

Chemotherapy

Chemotherapy uses drugs to kill cancer cells. Most anticancer drugs are injected into a vein (intravenous or IV) or into a muscle (intramuscular or IM); some are given by mouth (po).

Chemotherapy is a systemic treatment, meaning the drugs flow through the bloodstream to nearly every part of the body.

Chemotherapy is a systemic treatment, meaning the drugs flow through the bloodstream to nearly every part of the body.

In chemotherapy treatment, medicines are given to attack rapidly dividing cells, such as cancer cells. Chemotherapy is given when there is a possibility that cancer cells have spread from the primary cancer site to other parts of the body or as a way to help ensure there are no cancer cells hidden in the body.

Often, people who need many doses of IV chemotherapy receive the drugs through a large catheter or central line (a thin flexible tube) that is left in place until they have completed all their treatments. Commonly used central lines are Hickman® and Mediport®. One end of the catheter is placed into a large vein in the chest. The other end is outside the body or attached to a small device just under the skin. The rate of administration for the drug is carefully controlled by a small, computerized machine. These larger catheters are used because chemotherapy is damaging to smaller veins. Only specially trained providers, using a special noncoring needle designed specifically for use with a port, can use a central line to get blood samples. Patients and their families are shown how to care for the catheter and keep it clean.

Chemotherapy is generally given in cycles, some call it ‘rounds’ or ‘courses’, according to a time schedule. A treatment period is followed by a recovery period, then another treatment period, and so on.

Palliative chemotherapy is the word used to describe treatment with chemotherapy which is intended to improve the quality of life of people who are coping with cancer that has spread and for which there is no hope of cure or complete remission.

Side Effects of Chemotherapy

The side effects of chemotherapy depend upon the types of drugs and the doses the person receives along with how the person's body reacts to the treatments. Every person does not get every side effect, and some people get few, if any. The severity of side effects also varies from person to person and treatment to treatment. It is important for people to understand their chemotherapy treatment, common side effects, as well as serious side effects that they need to report to their health care provider.

Chemotherapy works by destroying or damaging cells that divide rapidly, primarily cancer cells. Unfortunately, there are healthy cells in our bodies that also divide rapidly that may be affected by the chemotherapy. These include blood cells, which fight infection, help the blood to clot, and carry oxygen to all parts of the body. When blood cells are affected by chemotherapy, people are more likely to get infections, bruise or bleed easily, and have less energy. People receiving chemotherapy do not have strong immune systems and therefore can get sick very quickly if they develop an infection. CHRs can help families and friends of patients receiving chemotherapy to understand the importance of preventing infections such as colds, flu, and other contagious illnesses from being transmitted to the person receiving chemotherapy treatment. Frequent hand washing and avoiding coughing, sneezing, and passing germs from one person to another are important ways to protect against infection.

It is very important to tell the health care provider if a person receiving chemotherapy has an oral temperature of 100.5 degrees or higher.

Other fast-growing, normal cells most likely to be affected are cells in the digestive tract, reproductive system, and hair follicles. The most common side effects of chemotherapy include diarrhea, fatigue (tiredness), hair loss, mouth sores (stomatitis), nausea, and vomiting.

Some chemotherapy drugs affect the reproductive system. For women this may mean experiencing temporary or permanent menopause. Men should discuss how chemotherapy may affect their sperm count and their ability to father children in the future. Some men choose to do sperm banking so they have a choice about their fertility if their sperm count remains low after chemotherapy treatment. Side effects of chemotherapy which may affect men and women's fertility are not reliable ways of preventing pregnancy. Reliable methods of birth control need to be used to prevent pregnancy during chemotherapy treatment.

Radiation

Radiation therapy uses high-energy rays to kill cancer cells or keep them from growing and dividing. Radiation therapy is also called radiation treatment, radiotherapy, x-ray therapy, cobalt therapy, electron beam therapy, or irradiation.

Radiation therapy is an effective way to treat many kinds of cancer in almost any part of the body. For some people, radiation is the only kind of treatment needed. Radiation can also be given in combination with surgery or chemotherapy. Radiation can be given before surgery to shrink a tumor or after surgery to destroy any cancer cells that remain.

Like surgery, radiation therapy is a local treatment; it affects cancer cells only in the treated area. The intensity of the treatments is carefully controlled so the cancer will be harmed and the effects to normal tissue will be minimal.

Radiation can be given externally or internally.

Like surgery, radiation therapy is a local treatment. It affects cancer cells only in the treated area.

External Radiation directs x-rays into the person's body from a machine placed a short distance away. External radiation treatments are usually administered five days a week for five to seven weeks on an outpatient basis. **People receiving external radiation are not radioactive during or after the treatment.**

Internal Radiation makes it possible to deliver a higher dose of radiation to the person's cancer using a radium implant. A small container of radioactive material is placed within or close to the cancerous tissue. The implant emits rays, therefore, people are hospitalized during treatment and visitors are restricted. Once the implant is removed, no radioactive material remains in the person.

People with prostate cancer may choose to be treated with radioactive "seeds" implanted into the prostate using a grid and needle through the perineum to transport the tiny seeds (about 70 of them) to the affected areas. These tiny seeds are left in place and do not have to be removed. As a precaution, patients should not hold young children on their laps until the radioactivity has worn off. Since these seeds can move, patients are asked to strain their urine for a week following the implant.

Even when a cure of the cancer is not possible, radiation therapy can still be helpful. Many people find the quality of their lives improved when radiation therapy is used to shrink tumors and reduce pressure, bleeding, pain, or other symptoms of cancer. This is called palliative treatment.

Side Effects of Radiation

The side effects of radiation therapy vary. In general, side effects depend upon which part of the body is being treated. For example, hair loss will only occur in the area being treated. Nausea and vomiting may accompany radiation treatment of the stomach area, and diarrhea may accompany radiation treatment of the bowel area. If the mouth and throat are treated, they may become very dry and sore and saliva may get very thick. The person may lose her or his sense of taste. If the person is receiving radiation therapy to a lung or the esophagus, she or he may have a severe sore throat causing difficulty in swallowing. The skin over the area being treated may become red and irritated.

Side effects usually start about two weeks after the start of treatment and peak in the fourth week, and may be intensified if the person is receiving chemotherapy at the same time. Generally, the side effects begin to go away 2 to 3 weeks after the last treatment, but may take several months to completely resolve. The treatment itself is painless.

Imagery

Healthy imagery may help provide a positive way for people to work with their treatment and healing journey. Choose words that support healing and positive imagery.

Think about any part of your body which you are concerned. Take a deep breath and breathe out thinking about letting go of any tension or any tightness you have in that part of your body. Breathe away any concern you have in that area. As you let go, allow your body to relax, feel your blood vessels get bigger allowing more oxygen to flow to that part of your body. Imagine healing elements flowing to that part of your body. By breathing in and out, taking nice slow relaxing breaths you are helping your body to heal. Breathe slowly and deeply and think of the following words, change them to make them your own to help your body heal…*"As I am relaxing, my body is making millions and millions of healthy strong new cells every minute. I imagine my body being bathed in sunlight and clear water, washing and dissolving the cancer cells and protecting the healthy cells. I see and feel my chemotherapy as a powerful cleanser, and radiation as beams of light removing cancer cells from my body while doing little harm to my healthy cells. My body is strong and can rapidly recover from surgery, radiation, or chemotherapy. My body welcomes the help of my medical treatment and works with it to free me of cancer*."

Check Your Understanding answers from page 5-3:
1)T, 2)F, 3)F, 4)T, 5)T, 6)T, 7)T, 8)T, 9)F, 10)F

Cancer Treatments: *What to Expect*

Helpful Questions to ask about Medical Tests and Procedures

Write down the questions you want to ask your provider. This will help you remember what you want to know and understand about your care.

Helpful Questions to ask about Medical Tests and Procedures

The following questions can be used to help patients, families, and CHRs understand common medical tests and procedures. Some times it is hard to know what to ask health care providers when they ask you if you have any questions.

Some people find it helpful to have the CHR, family member, or friend with them when they talk with their health care provider to be part of the discussion, to take notes, to help ask questions, or to listen. Bring a notebook to write down the questions you want to ask and what you learn. Ask your provider to explain any test results in ways you understand.

1. Why is this test or procedure being done?
2. Are there any reasons the test should not be done?
3. Does the patient need to sign a consent form?
4. Can the test be done if the patient is pregnant or breastfeeding?
5. If pregnant, should special precautions be taken?
6. How should the patient prepare for the test or procedure (i.e., can the patient eat before the test)?
7. Will there be any side effects or reactions?
8. How long will the test or procedure last?
9. Will there be any discomfort or pain?
10. Will the patient be hospitalized or be an outpatient?
11. Will the test or procedure require general or local anesthesia?
12. How should the patient take care of herself or himself afterwards?
13. Should someone drive the patient to and from the test or procedure if it is done as an outpatient?

Helpful Questions for Cancer Treatment

The following questions can be used to help patients and families understand common treatments for cancer.

- What is the specific cancer diagnosis?
- How advanced is the cancer? In other words, what is the stage of the cancer?
- What is the goal of treatment?
- What are the treatment choices?
- What treatment or combination of treatments is recommended? Why?
- What are the chances the treatment will be effective?
- How does each method of treatment work to treat the cancer?
- What are the short and long term risks of each treatment?
- What are the possible side effects of each treatment?
- What can be done before the treatment to avoid or decrease side effects?
- What symptoms or side effects should be reported to the health care provider immediately?
- Will the person have to change her or his normal activities during treatment?
- Are there any special precautions the person should take while on treatment?
- What tests, if any, will be done during and after treatment? What information will the test provide?
- Where will the treatment be given? Is it best for another person to drive the person to and from their treatment?
- How long will the treatment or treatments last?
- Will the person need to be away from home?
- What will be the follow-up plan after treatment is completed? Who will coordinate any follow-up care?
- How soon must the person decide about the treatment plan?
- Is a clinical trial recommended?

Managing With Grace

Artist Statement
Managing with Grace

While researching for this artwork, I discovered that several of the holistic methods for pain management were already part of our Native teachings. Laughter, touch, art, drumming, visualization, spirituality, and prayer are already within our ways of knowledge. When we use these things with traditional western medicine we can live a life that is pain-free or where our pain is manageable. This patient is feeling good with herself and her situation *because* both of these worlds are *working together*, in combination, to provide her with a life where her pain is manageable.

The eagle represents the strength of spirit our Native people have that is always there, supporting us in our times of need.

Cassandra Leigh Darrough
Paiute-Shoshone
August 12, 2010

Section 6

Cancer Pain: Assessment & Management

GOALS

Participants will gain a basic understanding of cancer pain, assessment skills used to evaluate pain and helpful ways to relieve pain.

OBJECTIVES

At the end of this section, each participant will be able to:

STATE two factors that influence cancer pain

EXPLAIN the difference between drug addiction and drug tolerance

PERFORM a pain assessment

UNDERSTAND ways to relieve pain

STATE two common side effects of narcotic medications

Table of Contents

Cancer Pain: Assessment & Management

Check Your Understanding

	TRUE	*FALSE*
1. If a person has a drug tolerance, it means the person is addicted to the drug.		
2. Everyone experiences pain differently.		
3. If a person has cancer, she or he can expect to experience strong physical pain.		
4. A person experiencing pain can appear as if they have no pain.		
5. Pain medicine works best if it is taken when the person is experiencing a lot of pain.		
6. The goal of pain management is to treat a person's pain without changing their ability to think clearly and do daily activities.		
7. Two common side effects of pain management with narcotic medicines are constipation and drowsiness.		
8. Physical cancer pain cannot be treated.		
9. Feeling tired, sad and stressed may affect a person's experience of pain.		
10. Pain management that includes a combination of treatment choices is a helpful way to relieve cancer pain.		

Cancer Pain

Every person with cancer should expect that pain management will be part of their cancer treatment. Cancer pain is often not voiced or misunderstood resulting in unnecessary suffering. Pain affects people's quality of life. Pain limits the ability to work and care for oneself and others; reduces a person's feelings of self control; and may cause hopelessness, anxiety, and depression. Pain can be a constant reminder of disease and the possibility of death.

Everyone experiences pain differently.

What is pain?

Pain is a sensation your body experiences when it is hurt or injured. It is often an indication that something is wrong. Pain can appear suddenly or come on more slowly. When we are hurt or injured, nerve fibers send messages to our brains and when the brain receives these messages we experience the sensation of pain. Pain may be experienced physically, emotionally and mentally. Pain may be felt in a variety of ways- throbbing, stabbing, aching, or pinching.

Pain can be acute or chronic. Acute pain begins suddenly and is usually sharp. It is usually a signal that body tissues are being injured in some way. The pain generally goes away when the injury heals. Chronic pain is present for long periods of time. Pain signals remain active in the nervous system for weeks, months or even years. Chronic pain can affect physical, mental and emotional well-being. Physically the person may experience loss of appetite and fatigue. Emotionally the person may experience feelings of sadness, depression, anger, and frustration. Mentally a person may feel forgetful or like they can't think clearly.

Each person's pain pathways and experience of pain are individual. Everyone experiences pain differently.

What affects a person's reaction to pain?

If a person is feeling tired, worried, helpless, hopeless, depressed, or easily discouraged, pain can seem worse, and it may be more difficult to cope with the pain.

A person who is well rested, feeling hopeful, and in control may feel the pain as less severe. The pain does not necessarily change, but the experience of the pain differs. When a person is not experiencing pain they might discover that they can breathe more deeply, move better, and enjoy their family and friends more.

Factors that influence pain include:

- Physical sensations: feeling tired or hungry
- Emotional stress
- Culture
- Financial worries
- Previous experience with pain
- Perception of amount of control one has over the situation
- Relationship with people one is with while experiencing pain

Does everyone with cancer experience physical pain?

No. For people in the early stages of cancer, less than half experience moderate to severe physical pain. About 3 out of 4 people in advanced stages of cancer experience physical pain.

Can cancer pain be relieved?

There are a variety of treatment options to relieve cancer pain and provide comfort. Peoples' beliefs about pain may interfere with health care provider's ability to provide pain relief. People may not report their pain thinking that is a sign of being "weak". They may fear becoming addicted to pain medicines or being labeled an addict. Some people are very proud and feel they must be "strong". They may not let family or health care providers know how much pain they are experiencing. The best way to relieve pain is to treat the cause.

What methods are available to relieve cancer pain?

Methods of pain relief include medication, medical or surgical procedures, and physical therapy. Complementary methods of pain management include relaxation, music, art, laughter, massage, imagery, meditation, and prayer. Pain specialists can also be consulted.

What types of medications are available?

Pain medications include non-narcotic and narcotic medications.

The best way to relieve pain is to treat the cause.

Cancer Pain: Assessment & Management

Pain Relief

A person who takes narcotics to relieve cancer pain, is not an "addict".

Will a person become addicted if she or he uses narcotics for pain relief?

No. A person who takes narcotics to relieve cancer pain is not an "addict". Narcotic use for cancer pain does not cause addiction.

Addiction is a common fear of people who need narcotics for pain relief. Family members are also often concerned about addiction. Narcotic addiction is defined as dependence upon the regular use of narcotics to satisfy physical and emotional needs, rather than use for specific medical reasons. Cancer pain relief is a medical reason for taking narcotics.

What is drug tolerance?

When certain drugs are taken regularly for a length of time, the body does not respond to them as well as it once did, and the drugs become less effective. Larger or more frequent doses must be taken to obtain the effect that was achieved with the original dose. People who take narcotics for pain control sometimes find that over time they need to take larger doses. This may be due to an increase in the pain or the development of drug tolerance. It may be necessary to increase the dose of narcotic pain medication to relieve increasing pain or to overcome drug tolerance.

What is NOT true about cancer pain?

People may have false beliefs or ideas about pain that hinder assessment and treatment. These ideas need to be discussed with people in order to assess and treat their cancer pain. Listen to their story and explain how these ideas interfere with effective pain relief. **These statements are NOT TRUE.**

- Cancer pain cannot be relieved; it is part of the disease.
- Worsening pain means the cancer is getting worse.
- Talking about pain will distract the doctor from treating the cancer.
- Being a "good patient" means not reporting or complaining about the pain.
- "Toughing it out" or enduring the pain is a sign of strength.
- Pain can build character or is a form of punishment.
- The strong medications must be saved for later when the pain gets really bad.
- A person taking pain medication for cancer pain relief will become addicted.

Pain Assessment Guide

It is important to accurately assess a person's level of pain in order to develop the best plan of care. Take time with the person to listen carefully to what they say. How do they look, what does their face or body show? Your genuine concern helps you to be a stronger resource, a better advocate, and a helpful support. Some people are OK talking about their pain, while other people may not feel comfortable talking about their pain.

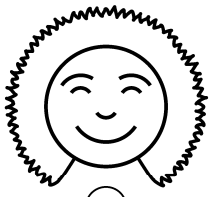
The following questions are helpful in assessing pain:

1. Where do you feel pain?
2. What does it feel like? Is it sharp, dull, throbbing, or steady?
3. When did it begin? When did it get worse?
4. Does the pain stay the same all the time? If not, when does it change (i.e., when you are eating, when you change position, at different times of the day)?
5. Is your pain there all the time? How often do you feel pain? Every day? During the week?
6. When you have pain, how long does your pain last?
7. Is there anything you do that brings about the pain?
8. Does the pain prevent you from doing any of your daily activities? If so, which ones?
9. Does your pain affect your sleep?
10. What relieves your pain?
11. What makes your pain worse?
12. What works for you to relieve your pain? What has not been helpful?
13. What have you done in the past to relieve other kinds of pain?
14. Is your pain less after you take your pain medication? If so, how much does it decrease and for how long?
15. It is important to take your pain medicines as prescribed. Have you been able to take your pain medicines?
16. It may be helpful to use a pain scale to track your pain.

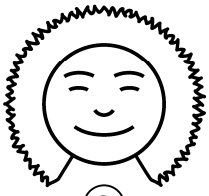
Cancer Pain: Assessment & Management

Pain Scale

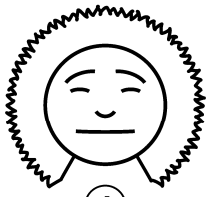
Some people easily discuss their pain, while other people do not talk about their pain.



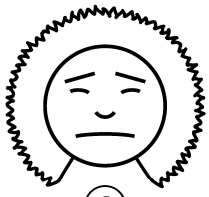
0
I have no pain
Akngirniatuq



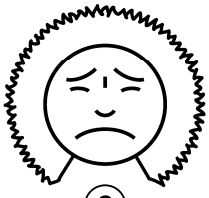
2
I have little pain
Ellma aknirnarquq



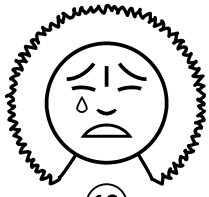
4
I have moderate pain
Cakneq akngirnarquq



6
I have much pain
Aknirnarqerpaagtuq



8
I have severe pain
Aknirnarqeqapiartuq



10
I have very severe pain
Caknenvak Akngiagua

Pain Scale

Using a scale to rate pain is one way to communicate a person's pain. This pain scale asks the person to rate their pain from 0 to 10.

0=no pain.

2=hurts a litlle bit, annoying

4=bothers me

6=uncomfortable, nagging

6=hurts a lot

8=very bad pain, intense

10=worse pain, cannot put up with it

A rainbow scale uses colors to define the severity of pain. A face scale works for children.

You can use the pain scale with the following questions.

1. What is your pain level at its worst?
2. What is your pain level most of the time?
3. What is your pain level at its least?
4. What is your pain level before you take your pain medication?
5. What is your pain level after you take your pain medication?

When using a pain scale to communicate a person's pain, be sure to say which pain scale you are using. For example: "Joe's pain was 6 on a 0 to 10 scale before he took his morphine. Twenty minutes after he took the morphine, Joe's pain was 2 on a 0 to 10 scale." Pain scales are effective tools to assess pain for an individual person, but are not used to compare one person's pain to another person's pain.

Helpful Reminders

1. Is the person able to use the pain treatment plan as prescribed?
2. Is the person getting adequate relief with the current pain management plan?
3. Is the person and family receiving support?

Pain Management

Pain management works best when the cause of the pain is adequately assessed and the cause treated.

The patient, the family, and the healthcare team work together to relieve cancer pain. Pain management is complex: it varies from person to person and for each person, it varies from one time to another. **Effective pain management is a continuous process requiring ongoing assessment, intervention, evaluation, and communication.** Ask the person if they are using pain control treatment as prescribed and if they are getting relief with the current pain management. Most people need to change their pain medications during the course of their cancer. It is important to provide support for the patient and her or his family during the pain management process.

Pain Management Principles

- Involve the person in their pain management plan to help decrease their anxiety, fear, and promote comfort.
- Learn what methods of pain relief work. It may be necessary to vary or combine pain relief methods. Use meditation or relaxation methods at the same time pain medication is given.
- Prevent pain before it starts or gets worse. This is important for long-term, chronic pain. By taking medications on a regular schedule, instead of on demand, the level of medication in the body remains constant. It takes less pain medication and less time to relieve pain when it is taken regularly and before a person has a lot of pain.
- Treat pain early. Do not wait for pain to become severe before doing something.
- Treat pain so it does not get in the way of eating, sleeping, or enjoying life.
- Reassure the person and their family: people do not become addicted to narcotics if narcotics are used to relieve physical pain.

Remember that pain may not be caused by the cancer.

The goal of pain care is to treat a person's cancer pain without decreasing their ability to think clearly and do daily activities.

Cancer Pain: Assessment & Management

Methods of Pain Management

The right drug and the right dose given at the right time can relieve most physical pain caused by cancer.

Every person has the right to have their pain assessed and adequately managed.

Methods of Pain Management

The best way to treat cancer pain is to first treat the cancer with chemotherapy, radiation, surgery, biological therapy, immunotherapy, or a combination of these approaches. Treatment of the cancer may not be completely successful in relieving the pain. Non-narcotic and narcotic pain relievers, also called analgesics, may be needed. Complementary methods are also effective in relieving pain and include: imagery, relaxation, music, art, humor, massage, and distraction.

Non-narcotic over-the-counter (OTC) medications
Many non-narcotic pain relievers can be purchased without a prescription from a health care provider. Nearly all nonprescription pain medicines use aspirin, acetaminophen (Tylenol®), or ibuprofen (Motrin®) to relieve pain. These medications can be given to the patient alone or in combination with prescribed medications. They decrease pain and swelling, and control fevers.

Although these medications can be obtained without a prescription, their use should be discussed with a health care provider.

Non-narcotic prescription pain medications
These medications are similar to over-the-counter pain medications but their dose is higher and they require a prescription. They are called nonsteroidal anti-inflammatory drugs (NSAIDs). Medications in the NSAID group may be useful for moderate to severe pain and can be used alone or in combination with other medications and pain control methods. NSAIDs do not cause drug tolerance or physical dependence. Examples are the higher strength Motrin® and Naprosyn®.

Narcotic medications used for cancer pain relief
Narcotic pain medications are available only with a prescription. Narcotics are medications that relieve pain and may cause drowsiness, sleep, or constipation. Historically, they came from the opium poppy (opiates). Today, many narcotics are manufactured synthetically by pharmaceutical companies to mimic the effects of opium (opioids).

Narcotic pain medications are used for moderate to severe pain. These medications do not change the cause of pain, but rather the person's perception of pain. Narcotic pain medications are frequently combined with aspirin or acetaminophen (Tylenol®) for more pain relief. For example, Tylenol #3® is a mixture of codeine and acetaminophen.

Common narcotic medications given for cancer pain are codeine, fentanyl, hydrocodone, hydromophone, morphine, and oxycodone. Most of these medications are taken orally in a pill or liquid form.

Refer to "Narcotic Side Effects & Comfort Care".

Cancer Pain: Assessment & Management

Methods of Pain Management

Other ways of giving pain medications include:

Rectal suppository: Medication is given to the person by gently pushing the suppository through the anal opening into the rectum. The medication dissolves in the rectum and is absorbed by the body. Morphine and hydromorphone can be given this way.

Transdermal patch: Medication is given to the person by placing a patch filled with medication on the skin. The medication is slowly absorbed through the skin. Some patches can last up to 72 hours. They work best if placed over fatty tissue and not bone. Patches stick better in areas with less hair and low moisture. The exact amount of medication delivered by this method may be difficult to control. Fentanyl is often given as a transdermal patch.

Injection: An injection uses a needle or tubing to place medications directly into the body. Some pain medications may be given by injection into a vein (intravenous), into a muscle (intramuscular), or directly into the spinal cord area (epidural or intrathecal) where the medication comes in direct contact with the nerves. Forms of morphine, fentanyl, and hydromorphone can be given by injections.

Other drugs to help reduce pain

The following types of non-narcotic drugs may be prescribed to relieve pain, improve the pain relief of narcotics, or decrease the side effects of narcotic pain relievers.

Antidepressants may relieve nerve pain and improve underlying depression and difficulty sleeping.

Antihistamines add to the pain relief effects of narcotics, help control nausea, and help people sleep.

Anti-anxiety drugs may be used to treat muscle spasms or anxiety.

Stimulants increase pain relief and reduce the drowsiness of narcotics.

Anticonvulsants are helpful to relieve pain from nerve injury caused by the cancer or cancer therapy.

Steroids are helpful for some chronic and acute cancer pain, particularly cancers that have invaded into nerves.

NSAIDs, such as ibuprofen, decrease inflammation and lessen post-surgical pain and the pain from bone metastasis (spreading of cancer into the bone).

When giving pain medications remember the KISS principle: Keep It Sanely Simple!

Nerve Blocks
When a local anesthetic (numbing medicine) is injected into or around a nerve, that nerve is no longer able to transmit impulses to the brain causing a temporary loss of feeling in the area served by that nerve. A nerve block uses a local anesthetic, sometimes combined with cortisone (a steroid medicine), to provide temporary pain relief. To control some types of severe pain, a nerve may be cut to try to achieve a long-term pain relief. After a nerve block, it is important to protect the treated area from injury caused by heat, cold or pressure.

Complementary Methods for Pain Relief

Complementary methods are used to increase the effect of medicines used for pain relief and to provide comfort.

ART
Art is a way for people to express themselves without words. Art such as drawing, sculpting, painting, or doing crafts may help people to express and let go of their feelings.

Distraction can be a powerful way of temporarily relieving even the most intense pain.

DISTRACTION
Distraction means turning one's attention to something other than the pain. Many people use this method without realizing it when they watch television or listen to the radio to "take their mind off" the pain. Other examples of distraction include playing games, telling stories, doing crafts, and reading.

Distraction may work better than medicine if pain is sudden and intense or if it is brief, lasting only 5 to 45 minutes. Distraction is helpful when the person is waiting for pain medicine to start working. If the pain is mild, distraction may help for hours.

Some people think that a person who can be distracted from pain does not have severe pain. This is not necessarily true. Distraction can be a powerful way of temporarily relieving even the most intense pain.

IMAGERY
Imagery uses imagination to create mental pictures or situations in the mind. Imagery is an intentional daydream or a form of self-hypnosis that uses sight, touch, hearing, smell, and taste. Positive, relaxing memories are revisited or fantasies created. Certain images may reduce pain during imagery and for hours afterward. If the person has to stay in bed, imagery may help to reduce the closed-in feeling. Imagery can help to relieve boredom, decrease anxiety, enhance relaxation, and promote sleep.

Cancer Pain: Assessment & Management

Complementary Methods for Pain Relief

LAUGHTER
Laughter can provide immediate distractions but it can also provide prolonged pain relief for several hours. Laughter releases endorphins which boosts our body's immune system. Laughter is like an internal massage of our tissues and organs.

MASSAGE
For pain relief, massage is most effective when using slow, steady, circular motions. Massage can be done with bare hands or with lotions or oils. Deep massage, light stroking, or brushing can be used to provide comfort and relaxation.
If the person is receiving radiation treatment, avoid massage in the treatment area.

MEDITATION AND PRAYER
Spiritual practices, rituals or ceremonies may provide comfort and healing. Meditation may involve repeating a word, phrase, or healing affirmation to focus the attention away from stressful thoughts or painful stimulus.
Music, singing, and/or drumming may also support a person's healing journey.

PLAY
Games, puzzles and toys are helpful in cancer treatment and pain management. Play with wind up toys, playdough ®, or other favorite distracting toys just for fun and enjoyment.

RELAXATION
Relaxation relieves pain or keeps it from getting worse by reducing tension in the muscles. It can help a person fall asleep, increase energy, decrease anxiety, and make other pain relief methods work better. Relaxation techniques include slow rhythmic breathing, massage, and the use of relaxation tapes.

SKIN STIMULATION
Skin stimulation is the use of pressure, friction or temperature change to excite the nerve endings in the skin. The same nerve pathways transmit the sensations of pain, heat, cold, and pressure to the brain. When the skin is stimulated with pressure, warmth, or cold, the pain sensation is lessened or blocked. Skin stimulation also alters the flow of blood to the affected area. Skin stimulation may decrease the pain or stop the pain entirely.

Accupunture can also be used to relieve pain and promote health.

NOTE: For people receiving radiation therapy, consult with the health care provider before using skin stimulation.

Check Your Understanding answers: 1)F, 2)T, 3)F, 4)T, 5)F, 6)T, 7)T, 8)F, 9)T, 10)T

Laughter provides pain relief & boosts our immune system.

Pain Diary: What's working

Use this chart to help identify pain characteristics: location, when it started, how long it lasts, the intensity, what helps, and what makes it worse.

Location:	Time started:	Duration:	Intensity (1-5):	What helps:	What makes the pain worse:

Narcotic Side Effects & Comfort Care

Not everyone experiences side effects from narcotic use. Some may be temporary as the body adjusts to the medication. Talk with a doctor before stopping or changing the dose.

Breathing Problems

Comfort Care

- Breathe deeply, cough, and change position every two hours.

Tell a health care provider if the person is having trouble breathing.

Constipation

Opiates slow down gastrointestinal functions and prolong the time it takes to empty the gastrointestinal tract. If you are on narcotics you need to be taking bowel medicine. Keep taking bowel medication as long as you are still using opiates.

Comfort Care

- Eat high fiber foods such as apples, pears, prunes, berries, dried fruit, potatoes, carrots, squash, corn, peas, whole grains, cereals, beans, and nuts.
- Drink plenty of water. 8 glasses of fluid per day is suggested unless you have fluid restrictions.
- Exercise. Walk for 30 minutes every day.

Drowsiness and Sleepiness

Opiates have a depressant effect on the central nervous system.

Comfort Care

- Avoid activities that require full alertness such as driving, cooking, or operating equipment.

Nausea and Vomiting

Usually temporary but may last up to 1 week.

The health care provider may order anti-nausea medications, to be given as a rectal suppository or by injection if unable to swallow a pill.

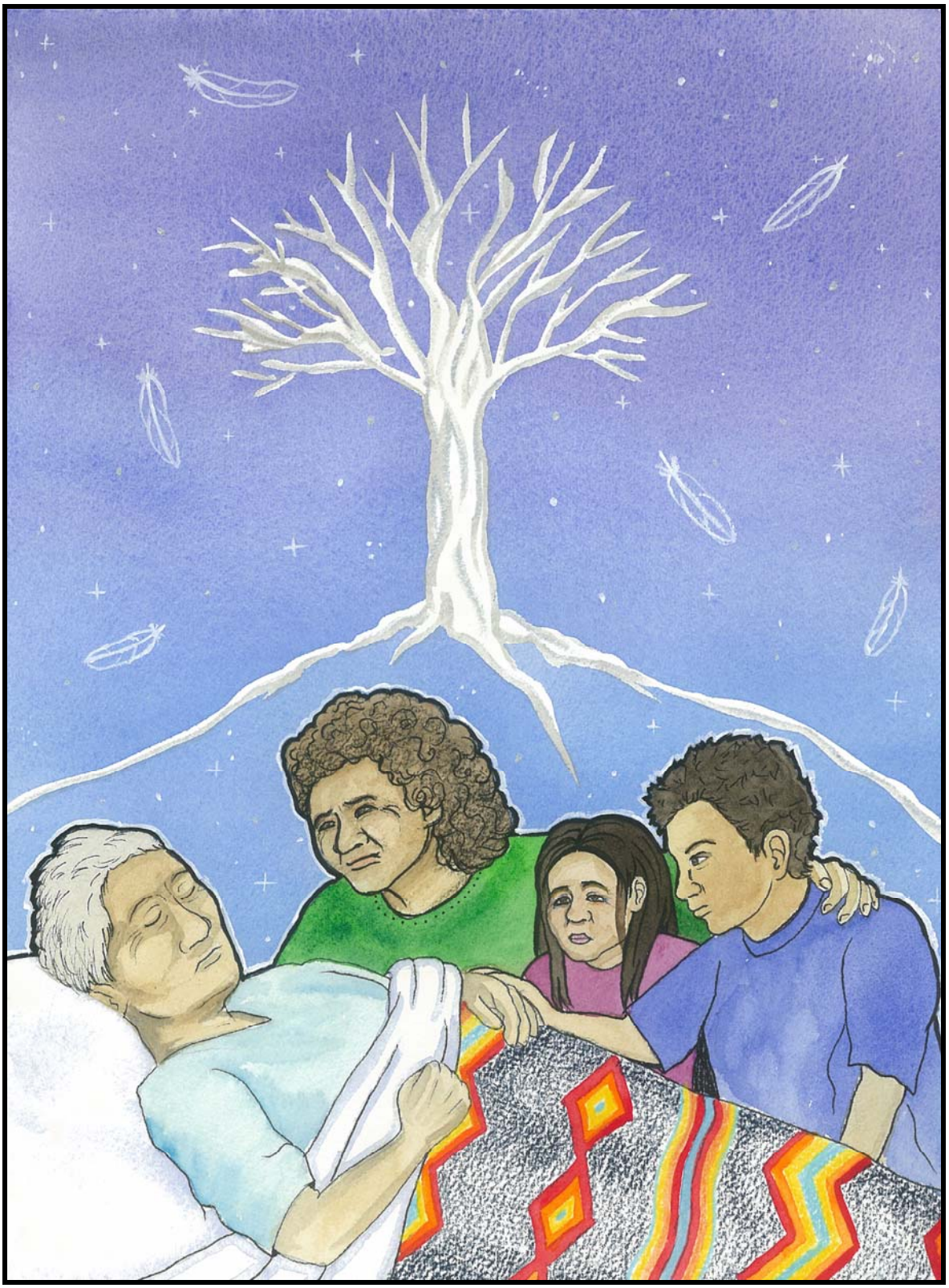
Urinary Retention (Difficulty emptying the bladder)

Comfort Care

- Urinate every 4 hours. Tell your health care provider if unable to urinate after 8 hours.

Other side effects are Hallucinations and Confusion.

Tell your health care provider.



Grieving Process

Artist Statement
Grieving Process
Life Cycle: Winter

For this artwork, I thought back on my own experience and gift of being with my grandmother when she walked on…and remembered her last teachings to me. The most important aspect I remember was that everyone was allowed to grieve, from all my elders to our youth…even my Grandmother. Our family came together at different times to comfort each other and I think it should be this way for all people. And in grieving our loss a wonderful gift to provide to our relative, friend or patient, is what was once provided to all of us, physical and emotional care, love, understanding and patience. It is a beautiful thing to see your relative off to the next world with your love regardless of the situation. It is also beautiful then…to recognize the path we each must take for ourselves through the grieving process.

Cassandra Leigh Darrough
Paiute-Shoshone
August 12, 2010

Section 7

Loss, Grief & End of Life Comfort Care

GOALS

Participants will gain a greater understanding of loss and grief by discussing the grieving process, end of life comfort care, and healthy coping skills.

OBJECTIVES

At the end of this section, each participant will be able to:

IDENTIFY feelings associated with the grieving process

IDENTIFY conditions affecting loss and grief

IDENTIFY ways to support people experiencing loss and grief

DISCUSS end of life comfort care

Table of Contents

Loss, Grief and End of Life Comfort Care

Check Your Understanding

		TRUE	*FALSE*
1.	Being diagnosed with cancer may cause feelings of personal loss.		
2.	All people respond the same way to a loss.		
3.	A person's reaction to loss and grief can be influenced by past losses.		
4.	Children of all ages can experience grief in response to loss.		
5.	Grief is a process of healing.		
6.	Family members may be in different parts of the grieving process at the same time.		
7.	Grief only lasts six months.		
8.	The goal of palliative care is to provide the best quality of life for people as they near the end of their life.		

Loss and Grief

Life is a sacred journey. It is about change, growth, discovery, movement, transformation, and continuously expanding your vision of what is possible; stretching your soul, learning to see clearly and deeply; listening to your intuition and taking courageous challenges at every step along the way. – Anonymous

Our lives are connected to and surrounded by people, animals, places, and things that are meaningful to us. In life, however nothing stays the same forever. People, animals, belongings, or places may change. People we care about may die or move away.

Loss can mean many different things to many different people. We may grieve the loss of a relationship, our independence, our health, our hopes and dreams. We may also grieve the loss of a physical belonging. When you lose a special belonging you may feel loss. Loss can be felt by one person or by a group. When a loved one or an elder dies, the entire community may grieve.

In July, a 64-year old man was hospitalized due to lung cancer. The cancer affected his physical strength and ability. When he returned to his community, he moved in with his daughter and her family who now had the responsibility to help care for his physical needs.

His role in the community changed. As his role changed, both he and his family may grieve the loss of how things used to be. Part of the grieving process of healing is looking for ways to celebrate each of our new roles and responsibilities. Consider new possibilities that emerge as roles and identities change.

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GRIEF IS A NATURAL PROCESS

Grief is one of the ways people react to losing someone or something they care about. How long and how deeply a person grieves varies depending upon the importance of the loss, past experiences, and the way an individual or family copes. Grief also changes with time. As people change and grow over time, their perception of loss may change.

This is especially true for children, whose understanding and experience of the feelings of grief will change as they grow and develop. Children may re-experience the initial grief each time they pass through a new developmental stage, such as going from pre-school to school-age or moving into the teenage years.

A song, a word, a smell, a piece of music may also trigger a memory or an emotional response to a past feeling of loss. "Grief bursts" are normal reactions that bubble to the surface as people are reminded of a person, animal, belonging, or place that had special meaning and is no longer the way it used to be.

Be kind and gentle with yourself as you reflect upon your loss. We each deal with sadness or grief in our own ways. Give yourself permission to grieve. Grieve for your losses and then allow yourself to dream new dreams.

The Grieving Process

Grief is often thought of as a process. During the grieving process people may experience: denial, anger, bargaining, depression, acceptance, and hope. These feelings and behaviors can occur in any order.

Each person's journey through the grieving process is unique. There is no right way or wrong way to grieve; there is only each person's way. An ancient African saying states, "There is no way out of the desert except through it." This could be said about grief. Understanding the grieving process provides a generalized map of the grieving experience, but each person will walk a different path. Each person will choose her or his own pace and will navigate using the tools provided by his or her culture, experience, and beliefs.

Family members may grieve differently and at a different pace as they experience their loss. As time passes, the intense pain associated with loss and grief will decrease.

Grief is a Natural Process

How long and how deeply a person grieves varies depending upon their loss, past experiences and the ways they cope.

Loss, Grief & End of Life Comfort Care

The Grieving Process

Healthy methods of coping support a person through their grieving journey.

Table 7.1: The Grieving Process

Table adapted from the Alaska Community Health Aide Manual 2005

STAGES OF GRIEF:	FEELINGS & BEHAVIOR:	Ways to help:
DENIAL Gives a person time for information to sink in, usually temporary.	▪ numbness ▪ shock ▪ disbelief	▪ Listen, give support. ▪ Try not to force the truth on the person unless it is really necessary. ▪ Understand denial will stop when the person is able to deal with the information. ▪ You may need to give this information again.
ANGER A way to express pain and guilt.	▪ crying ▪ anxiety ▪ tension ▪ pain ▪ feelings of guilt ▪ hostility towards staff, family, friends, or Spiritual Being	▪ Listen, give support. ▪ Let them know it is OK to be angry. ▪ Try not to take their anger personally. ▪ Help direct anger into safe activities: exercise, physical activities, writing
BARGAINING Attempts to reverse, delay, or change the loss.	▪ hopelessness ▪ bargain with Spiritual Being ▪ afraid to accept what has happened	▪ Listen, give support. ▪ Feelings of fear and helplessness are normal responses.
DEPRESSION Normal part of adjusting to loss, usually temporary.	▪ having no hope despair ▪ emptiness ▪ need and desire to cry ▪ withdrawal, apathy ▪ emotionally painful	▪ Listen, give support. ▪ Acknowledge sadness without trying to cheer them up. ▪ Social activities may be helpful to get person's mind off loss. ▪ When depression is severe, watch and listen for suicidal comments and ideas. Report concerns.
ACCEPTANCE Adjusting to the loss and returning to normal activities.	▪ peace ▪ emotional calm ▪ joy in life may return ▪ adjusting to reality	▪ Listen, give support. ▪ Acknowledge the change and let them tell you about it. ▪ Praise the person for the courage and strength it takes to face reality.
HOPE The experience of optimism with plans and goals.	▪ realistic plans ▪ belief in life	▪ Support goals and feelings that provide hope and comfort.

The Grieving Process

Denial

Denial is one way people can temporarily protect themselves from a loss. Common feelings include shock, disbelief and numbness. When describing how she felt after her husband's death, one woman said, "It seemed like it was happening to someone else." Denial gives us time to adjust. However, if it lasts too long it can be harmful. Denial becomes unhealthy when it keeps people from taking care of themselves.

Anger

A person may begin to feel the reality of the loss and tries to get rid of it or blame others. Health care providers, family, friends, or a Spiritual Being may be the target for a person's anger. It is common to feel rage, anxiety, or pain. It is helpful for people to find and use healthy ways to express anger, which do not harm the individual or other people. Anger kept inside a person can cause physical problems.

Bargaining

Bargaining is an attempt to postpone loss. The person tries to negotiate, often with their "Spiritual Being" in an effort to hold on to something important, or to change the loss to ease the pain. Bargaining includes a prize offered "for good behavior." People often set a "deadline" (one more day, the son's wedding), and include a promise that she or he will not ask for more if this wish is granted.

Depression

A person deeply feels the loss or anticipated loss. Feelings may include isolation, emptiness, and a lack of hope. The person may withdraw from people and activities they used to enjoy. A person may be overly tired, choosing to sleep all the time or experience a lack of appetite, not wanting to eat. Normal activities may require a lot of energy. Although these feelings are normal, depression is dangerous if a person forgets to take care of herself or himself, or becomes suicidal. Reinforce that the experience of depression is not a sign of weakness and a person should not feel embarrassed to talk about and share their feelings.

Acceptance and Hope

A person begins to understand and accept the loss or approaching loss. People begin to eat normally, sleep without difficulty, and return to work. It becomes easier to make decisions. This change can be subtle; good days start to outnumber the bad. A person can start to experience joy and meaning in their lives again. Acceptance does not mean forgetting, but rather using those memories to create a new life. People who are dying begin to make peace with themselves and their loved ones, and prepare to move on.

As time passes, the intense pain associated with loss and grief will decrease.

People move through grief in their own way at their own pace.

Conditions Affecting Loss & Grief

Sudden or Gradual Loss

Is the loss new or sudden? Has the person or family had time to work through their feelings of grief? If a person has time to prepare for the death of a loved one the grieving process may be shorter. Usually, when a person has been sick for a long while, there is time to say and do the things that need to be done before a person dies. When a person dies suddenly the family may not get to say "good-bye" or tell the person they are loved and will be missed. They may feel guilty if they were not with the person when they died. These and other kinds of "unfinished business" can make the grieving process more difficult.

Stage in Life

Consider how the grief will be different for each of two women in their late twenties who need a hysterectomy for cervical cancer. L.J. is 28 years old, happily married with a supportive husband and three children. She did not want to have any more children. Her main concerns are for the care of her children while she is in the hospital and the side effects from abdominal surgery. K.T. is also 28 years old and has never been pregnant. Her feelings of loss and grief about her hysterectomy may be influenced by her feelings about wanting to have children.

Age

Children and young people also grieve. Sometimes adults are so lost in their own grief that the grief of the young is not noticed. Young people of any age may grieve for a long time, continually leaving and coming back to their feelings of grief. Each person's reaction to loss is unique depending upon the relationship and degree of attachment. Whenever possible, it is helpful to prepare a child for a future loss or death. What is expected is often easier to cope with. Children often wonder: Did I cause this illness or death to happen?, Will this happen to me?, Who will take care of me now?

Past Loss and Grief

A current loss may remind a person of a past experience. In addition to coping with the current situation one may re-experience the grief of a past loss. For example, a woman severely damages her car in an accident but suffers only minor cuts and bruises. During the next few weeks she becomes depressed. This accident reminds her of a childhood accident in which a friend was killed. She is grieving again for the loss of her friend as well as coping with her present situation.

Coping with Loss & Grief

Healthy coping methods help a person move through the stages of grief while unhealthy behavior can result in a person getting stuck in their grief process. Moving through the grief process requires work, time and effort, and may be painful. Grief is not something we get over but something we begin to understand. Unhealthy ways to cope with loss and grief may include: substance abuse, verbal abuse, physical violence, sleeping all the time, not eating, or not caring for one's basic health needs. If grief is kept bottled up inside a person it may result in physical illness.

There are emotional, physical, social, cultural, and spiritual ways to cope with loss and grief that support a healing journey. Healthy ways to cope with loss and grief include taking care of yourself in all areas of your life.

Ways to cope include:

EMOTIONAL

- Accept the reality of your experience
- Forgive
- Accept mistakes
- Talk
- Share your feelings
- Journal, Draw
- Laugh
- Cry
- Recognize how important you are

PHYSICAL

- Get enough sleep
- Exercise
- Eat a well balanced diet
- Drink lots of water
- Avoid alcohol, tobacco and other harmful chemicals

SOCIAL/CULTURAL

- Participate in community events
- Attend support groups
- Visit with friends and family
- Learn to trust
- Listen to your elders, traditions and culture
- Create a balance in your life

SPIRITUAL

- Healing ceremonies
- Talking circles
- Dancing, Singing
- Being in Nature
- Prayer, Meditation, Relaxation
- Celebrate life's journey

Coping with Loss & Grief

Feelings:

Know them

Name them

Show them

Share them

–Liz Sunnyboy

Traditional Healer

Grief Shared is Grief Diminished.

Helping People Grieve

Often it is difficult and awkward to be with those who are grieving. As a caregiver you may feel or see people's pain and feel helpless, not knowing what to say or do. Sometimes the most important gift we can give someone who is hurting is to just be present in the moment with her or him. We are human beings and not human doings. Sometimes it is a hug, a simple touch of the hand, listening with our heart, or just being together that provides comfort and support as a person journeys along their healing path.

Identify
What has helped this person successfully cope with loss in the past? Help them to draw upon their past experience to deal with their current loss.

Be Available
The grieving process takes a long time: from months to years. After the ceremony, potlatch or funeral, people often leave the grieving person alone and they may feel very isolated. Check in on a regular basis and ask how they are doing. Offer your friendship.

Accept Expressions of Grief
Acknowledge the person's emotions and feelings. Don't try to take away their emotions. Share tears and laughter. People experiencing loss and grief may feel sadness, anger, resentment, guilt, confusion, relief, shame, fear, helplessness, loneliness, isolation, depression, or have difficulty making decisions. Allow people to openly express their feelings as long as it does not cause them or others harm.

Listen
Allow people to talk openly about their loss. Listen with your heart. This is an important part of the healing process and will help them move through their grief. Sometimes the most helpful thing a person can do is to listen, without offering advice or trying to cheer them up. Listening is more important than talking. You cannot take away their pain or loss but you can listen. There is healing in the telling of their story.

Encourage People Who have Experienced a Loss to Take Care of Themselves
Offer encouragement to help them create balance in their life.

Mark Your Calendar
Special occasions often bring back strong feelings of grief. During birthdays, holidays, anniversaries, and other special times it is common for people to revisit their grief. This is normal. This can be a special time to share and celebrate memories. A call, visit, or card provides comfort and support.

Care for Caregivers

Working with patients and families facing loss and grief and end of life decisions is very emotional. You may know the patient and family, which makes your role more stressful. In addition to helping the patient and family cope with their loss and grief, you have to cope with your own feelings and reactions. It is important to recognize your own needs and limitations, to take care of your own loss and feelings of grief.

When you take care of someone who is dying, he or she will die. As a health care provider the goal is usually to treat people or cure them. Caring for a dying patient requires you to let go of wanting to cure a person or make them better. The goal now becomes to have the best possible death experience. Be kind and gentle with yourself. Listen to your inner voice. Do the best you can and know that is enough.

HELPFUL SUGGESTIONS:

- Remember, the goal when caring for a person at the end of their life is not to provide a cure, but to help the patient and family reduce the stress of the illness, provide comfort, reduce pain, and adapt to changes in the patient's strength and ability to care for herself or himself.
- End of life care is a team effort. As a community health worker, you are not responsible to provide total end of life care. Clear expectations for your role and limitations need to be discussed with the family and the person's primary health care provider.
- It is OK to ask for help for yourself. Reach out for help and support, even before you think you need it.
- Talking with your supervisor, other caregivers, a minister, a spiritual healer or a counselor can help you cope with the emotional stress of end of life care. It is OK to express emotions, to cry, and to be sad.
- Learn to say "No". There are physical and emotional limits to what you can do for others.
- Find and use resources that teach you about loss and grief, the dying patient, and palliative and end of life comfort care.
- When people are grieving they can be angry and vent their feelings. Try not to take their anger personally.
- In order to care for others you need to charge your own batteries. Think about what brings passion and meaning to your life and fills you with joy. Laugh and celebrate those moments every day to prevent burnout.

Loss, Grief & End of Life Comfort Care

What is Palliative Care?

Death forces you to look at your own life and makes you learn how to live all over again in a completely different way.

– Tanya Matchian, CHP

What is Palliative Care?

Palliative care focuses on the dignity and quality of life, recognizing that death is part of the life cycle. Palliative care strives to help people have a pain-free life and to manage other symptoms so their days may be filled with comfort and dignity.

The goals of palliative care are to:

- Provide comfort by controlling pain and other symptoms.
- Help the patient and family understand the medical, physical, emotional, and spiritual issues of a life-threatening illness.
- Assist the patient and family in maintaining quality of life.

A cure may not be possible for all people with cancer. When all available curative treatments have been tried and are unsuccessful, the focus of care changes. The primary concern becomes quality of life. The goal is to provide support and care for people in the last phases of an incurable disease so they can live as fully and comfortably as possible. Treat people with respect and provide for the best quality of life until she or he takes their last breath and dies.

The Dying Process

For most dying patients, death is quiet and peaceful. They gradually get weaker and weaker until it is hard for them to do anything for themselves. They may spend most of their time sleeping. At some point their breathing changes, then slows down, and finally stops.

Death is as unique as the person experiencing it. Death comes in its own time and way. The following are common stages associated with the dying process.

Changes that may occur as a person approaches death.

1 to 3 months

- May begin to withdraw from the world and people in it, including family and friends.
- May stay in bed most of the time.
- May not feel like talking as much. Sitting quietly with a person and holding their hand or reliving happy memories can bring comfort and support.
- Loss of appetite. It is OK for the person to stop eating. Do not try to force them to eat or drink. Their physical body processes are working slower. They may need spiritual energy now, not physical.

1 to 2 weeks

- Sleeps almost all the time. Rarely opens eyes.
- May be disoriented, confused, or agitated. Picks at clothes and bedcovers.
- Talks to people we cannot see.

Physical changes include:

- Body temperature may increase or decrease.
- Pulse may increase or decrease.
- Breathing becomes irregular.
- More mucous in the throat, may sound congested.
- Drop in blood pressure.
- Increased sweating.
- Not eating, offer sips of water or juice.
- Body feels tired or heavy.
- Color becomes pale or bluish.
- Sleeps, but responds to voice or touch.

The Dying Process

Saying good-bye to a loved one is never easy. Sometimes we find ourselves at a loss for the right words to express our feelings.

Five ways to help say goodbye:

I love you

Thank you

Forgive me

I forgive you

Good bye

Loss, Grief & End of Life Comfort Care

May I Go?

Hospice of Anchorage

May I go now?
Don't you think the time is right?
May I say good-bye to pain-filled days and endless lonely nights?
I've lived my life and done my best, and an example tried to be,
So I can take the step beyond and set my spirit free?
I didn't want to go at first, I fought with all my might!
But something seems to draw me now to a warm and loving light.
I want to go!
I really do!
It's difficult to stay.
But I will try as best I can to live just one more day-
To give you time to care for me and share your love and fears
I know you're sad and are afraid because I see your tears.
I'll not be far, I promise that, and hope you'll always know
that my spirit will be close to you, wherever you may go.
Thank you so for loving me.
You know I loved you too.
That's why it's hard to say good-bye and end this life with you.
So hold me now, just one more time, and let me hear you say,
because you care so much for me.

Changes that may occur as a person approaches death.

Hours to Days

- Most people die within 3 to 14 days after they stop drinking and eating.
- May have a surge of energy, asking for favorite meal, visiting with friends or family, or talking clearly.
- Blood pressure drops.
- Eyes are half open, glassy, with tears.
- Breathing is irregular, stops and starts. Congestion sounds worse.
- Restless or no activity.
- Body feels cold and skin color changes: hands and feet may be purple, knees, ankles and elbows turn blotchy.
- Decreased urine output.
- May wet or soil bed.
- May become unresponsive, in a coma, as death nears.

Minutes

- Cannot be awakened.
- Breathing is very irregular, with gasps.
- Breaths are far apart, almost as if breathing has stopped.
- Heart stops and the physical body is now empty of its spirit.

End of Life Comfort Care

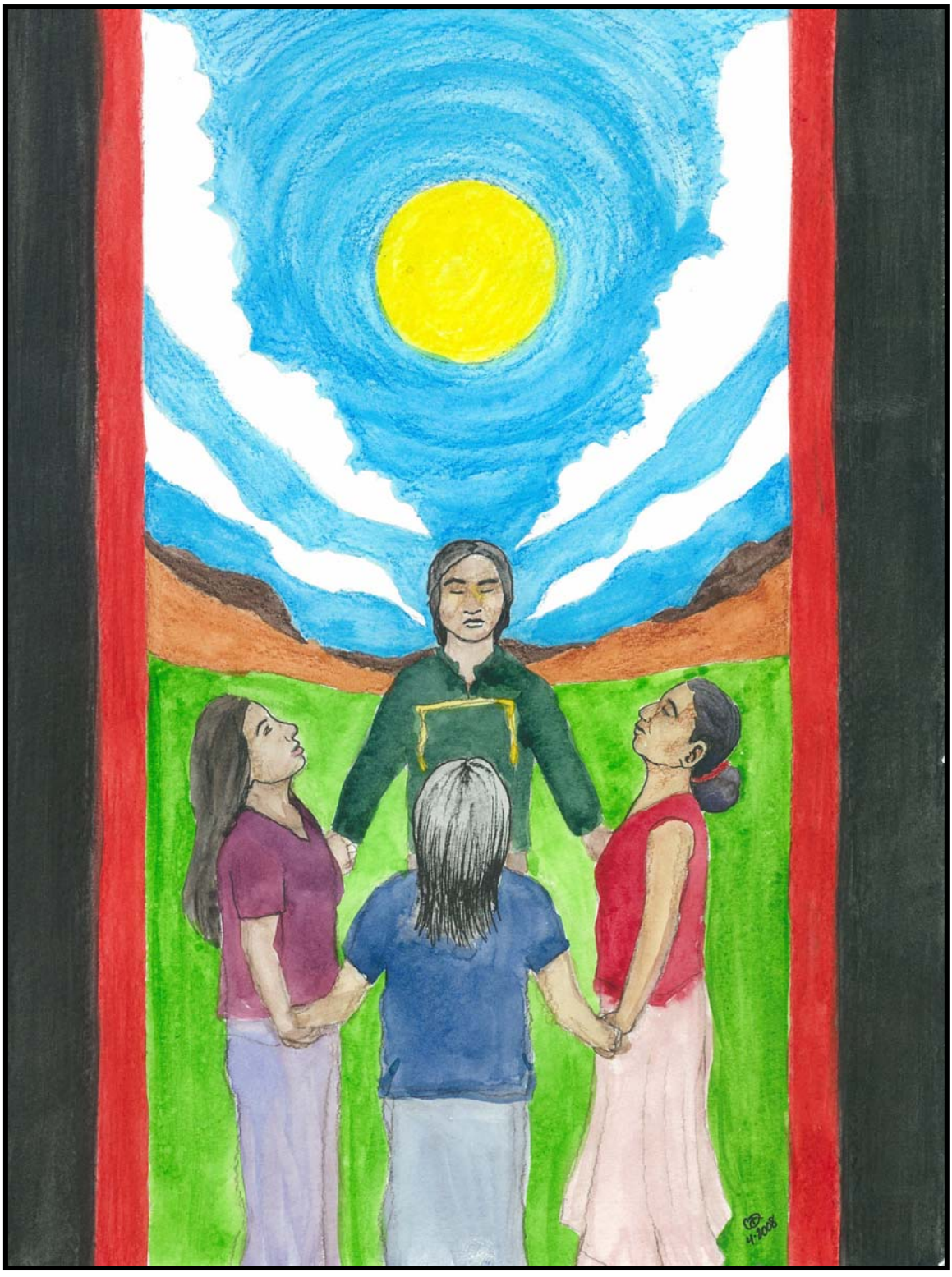
Death is a natural part of the life cycle for every living being. Each person approaches the end of her or his life in his or her own unique way. A person may choose to die at home in the village. If you have a person who is expected to die at home with family and friends, the following suggestions may provide comfort during this transition. It is important to support the person to live fully until she or he dies. Providing comfort care may include assessing and managing pain to promote the best quality of life possible. Also, it is important to honor and respect each person's beliefs and customs. Ask the person to share what is important to her or him during this phase of his or her life.

End of Life Comfort Care Adapted from Community Health Aide Manual 2005

Body Changes	What to Do
Appetite • Little or no interest in eating or drinking. • Dry mouth.	• Offer but do not force food or drink. • Do not use guilt to get person to eat or drink. • Ice chips or snow may help if the person's mouth is dry and uncomfortable. • Moisten the lips with Vaseline or a cool wash cloth. • Freeze a wash cloth and let the person suck on the edge.
Sleeping • Person will spend more time sleeping and become more difficult to awake.	• Sit with person. • Talk or sing to the person. • Share or make special memories. • Hold their hand. • Rub their feet.
Restlessness • Pulling at bedsheets or clothes • Trying to get out of bed. • Moving about from side to side	• Do not try to stop person from doing this. • Lightly massage their hand or forehead or rub their feet. • Read out loud. • Play music. Sing. • Keep person safe from falling out of bed.
Confusion • May be confused about time, place and who people are including family and close friends.	• Remind person of who you are. • Person may talk to people you cannot see. Listen, it may be important.
Seeing, Hearing, Speech • Hearing and eyesight not as good. • Eyes glaze over, may have tears. • Speech difficult to understand.	• Speak in normal voice tones. • Person may hear even if it looks like she or he is sleeping or unconscious. Always talk as if you are being heard and understood. There is no wrong thing to say, when what you say is from your heart. You will feel better if you take the chance to talk and hearing your words may comfort the person. • Keep bright lights from shining in eyes.
Bladder and stool • Loss of control of urine or bowels. • Decreased urine or dark urine. • Hard or no stools. • Tarry looking stools	• May use adult diapers, rubber sheets, mattress pad. • Ask doctor if a catheter would be helpful. • Use A and D ointment to protect the skin.

Breathing • Gurgling sounds in chest and throat • Breathing is irregular, shallow and even stops for 5 to 30 seconds, then person takes a deep breath. Fast, shallow, "panting". • A moaning sound when breathing out.	• Raise head of bed and turn her or him to their side. • Person is usually not in pain. These are normal noises associated with dying.
Skin • Arms or legs may become cold or hot, or change color.	• Keep person warm but not overheated. • Change sheets or clothes if person is sweating.
When Death Happens • Breathing and heartbeat stop. • Cannot wake person. • Eyelids may be partially open with eyes in a fixed stare. • Mouth may fall open slightly. • Anything left in bladder or rectum may be released as muscles relax. • The body may spasm after breathing stops. • You may hear a burp or a fart.	• Caring for the body after a person has died varies among cultures. Be respectful and supportive of the person's wishes before they died. • Learn how families and communities support each other during times of death. • Report to your referral doctor, who will ask at what time and where the person died.

Check Your Understanding answers: 1)T, 2)F, 3)T, 4)T, 5)T, 6)T, 7)F, 8)T



A New Day

Artist Statement
A New Day

I envision a day when the people will be well and healthy in mind, body and spirit. When drinking and drugs will no longer threaten and tear families apart. It will be when as Native people our risk for many diseases will no longer be the highest in the nation. When cancer no longer threatens the lives of those we love and care about. Then that will be a New Day.

In the cancer awareness and prevention circle this is the day we all look forward to. And this day will get closer and closer, as more and more people become aware of the risk factors for cancer. The CHRs in the picture are aware of this and so reach out and grasp the hands of those next to them. They create a link to knowledge and resources found within each other, by each other so that they learn from each other.

Cassandra Leigh Darrough
Paiute-Shoshone
April 19, 2008

Resources

What resources have you found helpful?
Whom do you ask or talk with when you want to learn more about cancer?
Where do you look for information on cancer: on the web, in a book, newspaper, magazine, other?

How do you know if you are reading accurate information?

The following are guidelines to help.
Web page addresses may end with the following:

- .edu for educational or research material
- .org for organization
- .gov for government resources
- .com for commercial products

Ask yourself the following questions.

Who says so?

Look for author's name, title or position, and organization.

- Is it clear who is responsible for the contents of the page?
- Is there a link to a page describing the purpose of the sponsoring organization?
- Is there a way to verify the page? (phone number, address, or contact information)
- Is it clear who wrote the material and are the author's qualifications for writing on this topic stated?

Can I trust these facts?

- Are the sources for any facts or information listed?
- Is it clear who is responsible for content accuracy?
- If there are charts/graphs are they clearly labeled and easy to read and understand?

Why are they telling me this?

- Is the information provided as a public service?
- Is the information free of advertising?
- If there is advertising, can you tell it apart from the informational content?

Is the information up-to-date?

- Are there dates to indicate: when it was written, when it was placed on the web, when it was last updated?
- If there are graphs/charts, is it clear when the information was gathered?

WHERE TO FIND HELP AND SUPPORT

Listed below are a few of the many helpful cancer resources to find reliable information if someone asks you a question and you want to find the best answer.

American Cancer Society (ACS)

www.cancer.org
1-800-478-9355
Provides cancer information and support services. In some areas of the country, ACS has a special program to support American Indian and Alaska Native peoples. For information about how to talk with children about cancer and suggested reading materials for parents and their children see this ACS link:
www.cancer.org/docroot/ESN/content/ESN_2_1x_Talking_with_Children_About_Cancer.asp

National Cancer Institute
Cancer Information Service (CIS)

www.cancer.gov
Provides accurate and up-to-date cancer information.

Native C.I.R.C.L.E.
(Cancer Information Resource Center and Learning Exchange)

http://cancercenter.mayo.edu/native_circle.cfm
1-877-372-1617
A cancer resource center for American Indian and Alaska Native people. Includes an education resource center to order free materials including pamphlets, movies, and information for children.

American Institute for Cancer Research (AICR)

http://www.aicr.org
1-800-843-8114
Researches the role of diet and nutrition in the prevention and treatment of cancer. AICR offers a variety of information to help you eat and live more healthfully, including a recipe corner.

Air Charity Network

http://www.aircharitynetwork.org/
1-877-621-7177
Air Charity Network™ (ACN) provides access for people needing free air transportation to specialized health care facilities or distant destinations due to family, community or national crisis. CHRs can work with hospitals and clinic staff to bring this service to American Indian and Alaska Native patients who are in need of transportation.

Cancer*Care*
www.cancercare.org
1-800-813-HOPE (4673)
Helps people face the many challenges of a cancer diagnosis. Provides free telephone education workshops. Additionally, *Helping Children Understand Cancer* is available at this link.
http://www.cancercare.org/pdf/fact_sheets/fs_children_en.pdf

Cancer Hope Network
www.cancerhopenetwork.org
1-877-Hopenet (467-3638)
Matches patients with trained volunteers who have experienced cancer. Provides support and hope for cancer survivors.

Kids Health
Kidshealth.org
KidsHealth is a website providing doctor-approved health information about children from before birth through adolescence.

Locks of Love
www.locksoflove.org
1-888-896-1588
Accepts donated hair to make wigs for children. Provides free wigs to financially disadvantaged children with long-term medical hair loss.

Pantene Beautiful Lengths
http://www.beautifullengths.com/en_US/index_home.jsp
Accepts donated hair to make wigs for women who have lost their hair from cancer.

Lance Armstrong Foundation
http://www.livestrong.org
1-866-467-7205
Provides information and resources for people living with cancer. Website includes inspiring cancer survivor stories.

Patient Advocate Foundation
www.patientadvocate.org
1-800-532-5274
Ensures equal access to health care for all Americans.

Hospice Foundation of America (HFA)
www.hospicefoundation.org
1-800-854-3402 Mon-Fri, 8:30-5:30 ET
Provides quality end-of-life care and support for patients and their families.

Resources

Helpful Resources

Breast Cancer Resources

Breast Cancer.org
breastcancer.org
Provides helpful and easy to understand breast cancer information.

Susan G. Komen Breast Cancer Foundation
www.komen.org
1-877 GO KOMEN (1-877-465-6636)
Dedicated to breast cancer education, support, and research.

Colon Cancer Resource

Colon Cancer Alliance, Inc.
www.ccalliance.org
1-877-422-2030
Provides information, support, education, research, and advocacy for people about colorectal cancer.

Leukemia and Lymphoma Resource

Leukemia and Lymphoma Society
www.lls.org
1-800-955-4572
Provides support and information about blood-related cancers, and limited financial assistance for patients who qualify.

Lung Cancer Resource

American Lung Association (ALA)
www.lungusa.org
1-800-548-8252
Works to prevent lung disease and promote lung health through education, community service, advocacy, and research.

Prostate Cancer Resource

US TOO! International, Inc.
www.ustoo.com
1-800-808-7866
Provides support, counseling, and education to assist men, their partners, and families in understanding prostate cancer.

ONLINE HEALTH INFORMATION RESOURCES

Native American Cancer Research
http://natamcancer.org/naces.html
This community based, American Indian, non-profit resource seeks to reduce cancer incidence and mortality among American Indian and Alaska Native people.

Understanding Cancer Risk
http://understandingrisk.cancer.gov/
Website offers interactive activities to understand cancer risk.

Your Disease Risk
http://www.yourdiseaserisk.wustl.edu/
Center for Cancer Prevention is an interactive site to assess health and risk for cancer and other chronic diseases.

MOVIES FOR SHARING

The following six movies are recommended by CHRs to share cancer understandings with people about ways to stay healthy and decrease cancer risk.

Movies are available free of charge from:
Native CIRCLE nativecircle@mayo.edu 1 877-372-1617
or may be viewed at the Arctic Health website
http://www.arctichealth.org/anthcvideos.php
Visit the CHAP cancer CME page to learn more:
http://akchap.org/CancerCME.cmf

Movie Titles:

- Awakening Choices: Colon Health, Our Stories
- Cancer in the Great Land
- Conversations about Breast Cancer
- The Story Basket: Weaving Breast Health into Our Lives
- Staying Strong Staying Healthy: Alaska Native Men Speak Out About Cancer
- Understanding: Stepping into the Light

MOVIE DESCRIPTIONS

Awakening Choices: Colon Health, Our Stories
Colorectal cancer is the second leading cause of cancer death for many American Indian and Alaska Native people, yet it can be prevented. Experience stories of wellness; celebrate the gift of life through the beauty of Alaska Native people's songs, dances, and

culture. We learn the importance of colorectal screening through the stories of Alaska Native people. Can be viewed at the Arctic Health website http://www.arctichealth.org/anthcvideos.php

Cancer in the Great Land
What is cancer? How does cancer develop? What can we do to decrease our cancer risk or prevent cancer? 'Cancer in the Great Land', filmed in Alaska, explores these common concerns about cancer. This movie has been shown and well received at health fairs, community gatherings, and as part of school health presentations.

Conversations about Breast Cancer
Three women share their experience of being diagnosed with breast cancer. We journey with them through chemotherapy and radiation treatment. They share ways to live well through a cancer diagnosis and treatment. This movie is helpful to learn more about breast cancer treatment and ways to provide comfort and support while someone is undergoing cancer treatment. Additional information on this DVD shows a self breast exam, clinical breast exam, and mammogram.

The Story Basket: Weaving Breast Health into Our Lives
Woven together in 'The Story Basket' are three important choices women make to find breast cancer early when it can be best treated. We see a clinical breast exam, a mammogram and a self-breast exam. Learn the vertical breast exam pattern. Women talk about the importance of breast health. Can be viewed at the Arctic Health website http://www.arctichealth.org/anthcvideos.php

Staying Strong Staying Healthy: Alaska Native Men Speak Out About Cancer
Experience the resilient stories of men whose lives have been affected by prostate, colorectal and testicular cancer. Alaska Native men speak out about ways to prevent cancer, ways to decrease cancer risk, and ways to find and treat cancer early. Part two of the movie shows a clinical testicular exam and a young man doing a self-testicular exam. Can be viewed at the Arctic Health website http://www.arctichealth.org/anthcvideos.php

Understanding: Stepping into the Light
The cancer education play, 'Understanding' was adapted for television. An all-Alaska Native cast explores many challenging and sensitive themes including emotions associated with a cancer diagnosis, treatment, pain, end-of-life, and loss and grief. Healthy lifestyle choices and recommended cancer screening exams are voiced. We hear Alaska Native people's stories of hope and resilience. 'Understanding' is a call to action. It is an invitation to come together to engage in meaningful conversations to illuminate possibilities and choice.

Understanding New Words

Adjuvant Therapy (AD-joo-vant THER-uh-pee)
Anything that aids in removing or preventing a disease.

Benign (beh-NINE)
A tumor that is not cancer; it does not invade nearby tissue or spread to other parts of the body.

Biopsy (BY-op-see)
The removal of a sample of tissue that is examined under a microscope (by a specially trained doctor called a pathologist) to look for cancer cells.

Bone Marrow/Stem Cell Transplant
Diseased or damaged bone marrow is destroyed by high dose treatments of anticancer drugs or radiation and replaced with healthy stem cells (blood forming cells) taken from the patient before treatment or donated by another person.

Bone Scan
Test showing images of bones on a computer screen or on film. A small amount of a radioactive substance is injected into the bloodstream and collects in the bones.

Cancer
A word for more than 100 different diseases in which abnormal cells divide without control or order.

Carcinogen (car-SIN-oh-gin)
A substance or agent that is known to cause cancer.

Carcinogenesis (car-SIN-oh-JEN-eh-sis)
The process of a normal cell changing to a cancer cell.

Carcinoma (car-cin-OH-ma)
A cancer that begins in the epithelium, the body's skin and tissues that line the internal organs. Eighty to 90% of all cancers are carcinomas.

Cell
Basic unit or building block of human tissue.

Chemotherapy (kee-moh-THER-up-pee)
Treatment with cancer fighting drugs.

Vocabulary

Chromosomes (KRO-muh-soh-mz)
Threadlike structures within each cell that contain a double strand of DNA with chemical information for cell function and replication. Human cells have 46 chromosomes, 23 from mother and 23 from father.

Clinical Breast Exam (CBE)
Breast exam to discover changes in the breast tissue done by a health care provider.

Colonoscopy (KOH-lun-OSS-koh-pee)
A procedure in which a health care provider looks inside the entire colon and rectum using a thin, flexible, lighted tube called a colonoscope, to find and remove polyps before they become cancer.

Colposcopy (Kol- POSS-koh-pee)
A visual exam of the cervix using a colposcope to magnify cells.

Computed Tomography CAT or CT Scan
An x-ray test using a computer to make a picture of the body.

Cure
Restoration of health; recovery from disease; free from cancer.

Deoxyribonucleic Acid (DNA) (dee-OX-see-RY-boh-noo-clay-ick A-sid) The substance of heredity carrying the genetic information that cells need to replicate and to produce proteins.

Differentiated (DIF-uh-REN-shee-ated)
Describes how closely abnormal tumor cells look like normal cells.

Digital Rectal Exam (DRE)
An exam done by gently inserting a gloved finger into the rectum to check for abnormalities of the rectum. The exam, in men, also checks for changes of the prostate gland.

Distant
Cancer has spread to other organs and systems of the body.

DNA Repair Genes
Special genes that fix errors that happen when a cell copies its' DNA before dividing to make 2 new cells. They protect the body from cancer causing mutations (errors).

Epithelium (EP-ih-THEE-lee-um)
Tissues that line the skin and internal organs.

Genes (jeens)
The basic units of heredity.

Gene Testing (jeen testing)
Examination of a person's DNA, usually from a blood sample, for a particular gene mutation.

Heredity (Ha-reh-DUH-tee)
The genetic information passed from parents to their children.

Hereditary Cancer (Ha-RED-ih-tair-ee CAN-sir)
A cancer caused by a mutated gene inherited from a parent.

Hereditary Cancer Syndrome (Ha-RED-ih-tair-ee CAN-sir SIN-drohm)
An inherited mutated gene causes more than one kind of cancer in a family.

Hope
A positive outlook with desire or expectation for the best outcome.

Hormone Therapy
Treatment of cancer by removing or adding hormones.

Immune System
The body's system that resists and fights disease. It includes the white blood cells and antibodies.

Incidence (In-sih-dence)
The number of people newly diagnosed each year with a disease. For example, if a population initially contains 1,000 non-diseased persons and 14 develop a condition over one year of observation, the incidence rate is 14 cases per 1,000 persons, 1.4%.

In-Situ (in-SIT-ooh)
Cancer cells are in place and have not invaded normal surrounding tissue.

Intravenous (IV) (in-truh-VEE-nus)
Within or into a vein, for example chemotherapy given into the vein.

Invasive
Cancer cells spreading beyond the upper most layer into healthy tissue.

Latency (Lay-ten-see)
An effect that does not appear for a long time.

Leukemia (loo-KEE-mee-uh)
A cancer of the white blood cells formed from the blood-forming tissues, mainly the bone marrow, lymph nodes and spleen.

Local
Cancer found only in the organ where the cancer first started to grow.

Local Treatment
Only affects cancer in the treated area. Surgery and radiation are local treatments.

Lower GI series (Barium Enema)
A series of x-rays, taken after a person drinks a barium solution, which shows the large intestine or colon.

Vocabulary

Lymphoma (lim-FO-ma)
A cancer that develops in the lymphatic system, part of the body's immune defense system.

Magnetic Resonance Imaging (MRI) (mag-NEH-tik REH-zoh-nants IH-muh-jing) A procedure using a magnet linked to a computer to make pictures of areas inside the body.

Malignant (muh-LIG-nant)
A tumor that is cancer and has the ability to spread to other parts of the body.

Mammogram (MAM-oh-gram)
A special x-ray of the breast.

Metastasis (meh-TAS-tuh-sis)
The spread of cancer from one part of the body to another part of the body through the lymph system or blood system.

Mortality Rate
The number of deaths in a population from a specific disease. Mortality rate is stated in units of deaths per 1000 individuals per year; thus, a mortality rate of 9.5 in a population of 100,000 would mean 950 deaths per year in that entire population.

Mutation (myoo-TAY-shun)
A mistake or error in a gene.

Myeloma (my-eh-LOW-muh)
A cancer that starts in plasma cells made in the bone marrow.

Needle Biopsy
Removing a tiny piece of tissue with a needle.

Oncogenes (ON-koh-jeens)
Genes that direct the normal growth of cells but, when damaged, can cause the growth of cancer.

Oncologist (on-KAH-loh-jist)
A medical doctor who specializes in the care of people with cancer.

Pap Smear or Pap Test
An exam, done by a health care provider, to take a sample of cervical cells to look for changes that may be precancer or cancer.

Pathologist (puh-THAH-loh-jist)
A medical doctor who diagnoses diseases by studying cells and tissues under a microscope.

Prevention (pree-VEN-shun)
Eliminate or decrease disease. Health promotion and education to support wellness.

Primary Site or Primary Tumor Site
The location where the cancer first starts to grow.

Prognosis (prog-NO-sis)
The probable outcome or course of a disease; the chance of recovery.

Radiation Oncologist
A medical doctor who specializes in using radiation to treat cancer.

Radiation Therapy
Treatment with high-energy rays to kill or damage cancer cells. External radiation therapy is the use of a machine to aim high-energy rays at the cancer. Internal radiation therapy is the placement of radioactive material inside the body as close as possible to the cancer.

Regional
Cancer has spread to the surrounding tissues or lymph nodes.

Remission (ree-MISH-un)
Disappearance of the signs and symptoms of cancer. Remission can be temporary or permanent.

Risk Factor
Something in an individual, in her or his lifestyle, or environment, which increases the chance of developing cancer.

Sarcoma (sar-KOH-muh)
A cancer that starts to grow in bone, fat, muscle, nerve, joint, blood vessel, or deep skin tissues.

Screening
Checking for disease when there are no symptoms.

Secondhand smoke (also called passive or environmental tobacco smoke)
This is a mixture of the smoke given off by the burning end of tobacco products and the smoke exhaled by smokers. It contains the same cancer-causing agents or carcinogens as the smoke inhaled by smokers.

Sigmoidoscopy (sig-moy-DOS-koh-pee)
A procedure in which a health care provider looks inside the rectum and lower one third of the colon, called the descending or sigmoid colon, using a thin, flexible, lighted tube called a sigmoidoscope.

Sonogram (SAW-nuh-gram)
Picture from an ultrasound.

Sporadic Cancer (spuh-RAD-ik Can-sir)
A cancer that happens once in awhile by chance. Most cancers are sporadic.

Vocabulary

Stage
Describes how far the cancer has spread from the original site to other parts of the body (i.e., in-situ, local, regional, distant).

Stereotactic Breast Biopsy (stair-ee-oh-TAK-tik breast by-OP-see)
A small piece of breast tissue is taken with a needle using x-rays to locate the suspicious area.

Surgeon (SIR-jin)
A medical doctor who does operations.

Surgery (SIR-jih-ree)
An operation.

Survival Rate
The number of people in a population with a disease that survive that disease; it may be given a time frame, e.g. the 5 year survival rate of breast cancer is the number of people with breast cancer who are still living 5 years after the diagnosis of cancer. Doctors use survival rates to estimate the patient's prognosis over time, for example: one, five, and ten years.

Systemic Treatment
The delivery of medicine throughout the entire body. Chemotherapy is a systemic treatment.

Testicular Exam (tes-TIK-u-ler EX-am)
An exam done to feel for lumps in the testes to help find testicular cancer early.

Tissue
Group or layer of cells that is alike and work together to perform body functions. Tissue makes up the organs of the body.

Tumor (TOO-mer)
An abnormal growth of cells or tissues; tumors may be benign (not cancer) or malignant (cancer).

Tumor Grade
Describes how fast a cancer tumor is growing and how closely the abnormal cells look like normal cells.

Ultrasound (UHL-truh-sound)
An exam in which sound waves are bounced off tissues and the echoes are converted into a picture called a sonogram.

Upper GI Series (Barium Swallow)
A series of x-rays, taken after a person drinks a barium solution, which shows the upper digestive organs.

X-rays
High energy radiation used in low doses to diagnose disease or injury. Also used in high doses to treat cancer (radiation therapy).

Activities

Share your knowledge and play these interactive games with family, friends, and the people in your community. Have fun learning!

Activity: Penny Game

Comfort Kit: Give each participant a Comfort Kit that includes a chocolate kiss, sticker, penny, band-aide and eraser.

- The **chocolate kiss** is to comfort you when you are feeling sad.
- The **sticker** is to remind you that we will all stick together and help each other.
- The **penny** is to remind you that you are valuable and special.
- The **band-aide** is to remind you to heal hurt feelings in your friends and in yourself.
- The **eraser** is to remind you that everyone makes mistakes and that it is okay

Play the Penny Game

Give each person a penny. Have participants stand next to each other in a circle. One person reads the penny story aloud. When you hear the word **right**, participants pass their penny to the person on their **right**. When they hear the word **left** they pass their penny to the person on their **left**. After reading the penny story, invite people to share what they learned. You can also read the story again without passing the penny and have people listen more carefully to the messages.

CHR suggestion: Invite participants to color their penny with a marker and pass it forward, giving it to a person and sharing something they have learned. The person they give their penny to is invited to give the penny to a new person, continuing to share wellness ways, keeping the conversation going and expanding.

Have fun playing. ☺

You can make your own penny story by using the words right and left to share healthy messages.

Think about the ways people in your community like to learn and share information. Create ways to share cancer understanding using their preferred ways.

The Penny Story

Welcome. It's a right fine day to learn the importance of wellness ways to prevent cancer. The right way to take care of your health is what's right for you, but there are some things which should not be left out. Native traditional ways of healing and wellness are right important to live well along your journey. Diet is important. Eat foods from the right food groups including 5 servings of fruits and vegetables everyday, including weekends and holidays. No days are left out. Yes, you are right, 5 is fine but 9 is divine. Have a right fine time with your family picking berries and greens. Grow a garden-it's a right fun way to eat healthy.

Exercise shouldn't be left out. Move your body. Shake your right arm and your left arm. Dance, wiggle, squirm for 30 minutes every day. Your body is created to move. Each new journey starts with just one step, move your left foot or your right foot, but step forward for good health.

When it comes to cancer screening, don't get left behind. Right away, schedule those tests which are right for you. Listen up with your right ear and your left ear…colon cancer screening saves lives and prevents colon cancer. Men and women, love your colons! Women, remember self breast exams, clinical breast exams, mammograms and pap smears. Tell your friends, your family, and your neighbors on the left. Oh yes, don't forget those special people on the right. Write reminders. Lovingly remind the right fine men in your life to do the right screening exams for their health. We don't want them left out. Testicular, prostate, and colon exams are right important for men's health.

You are the heart of cancer prevention. Right away, you can make a difference by the choices you make! Share your new knowledge. Together we can all learn the right screening exams and make healthy choices. Right on!

Colorectal Wellness Penny Story Game

Complete your colorectal wellness story by filling in the blanks.

Hello! It's a **right** fine time to learn the importance of colorectal wellness exams. When it comes to colorectal screening, you need to start **right** off at age _____, or age _____or younger if you have a family history of colorectal cancer.

Mrs. **Right** wanted to stay healthy, so **right** away on her 50th birthday she made an appointment to have a screening exam. After a few weeks, she **left** for the clinic where a doctor or trained health care provider can do a _____ or a _____ , 2 types of screening exams. Mrs. **Right** encouraged her neighbors on the **left** to get a screening exam. It's a **right** important way to stay healthy. She decided to **write** to her mother to remind her that a colon exam was **right** important.

Mrs. **Right** called her sisters and brother, "Don't be **left** out – have a wellness screening exam when you are healthy to stay healthy. It can save _____ _____ !" Mrs. **Right** said, "It makes me feel **right** happy. I am not **left** wondering if I have colorectal _____." After Mrs. **Right** hung up the phone, she realized that she **left** something out. So Mrs. **Right** called her sisters and brother back and told them about the **right** way to take the stool card test. She explained that men and women between the ages of 50 and 75 should complete a stool card test every year. Mrs. **Right** also reminded them that medicines like aspirin, ibuprofen and vitamin C should be stopped 7 days before starting the FOBT stool card test, and red meats like beef, liver and lamb should be stopped 3 days before the FOBT stool card test.

✯ 40	✯ embarrassed	✯ family	✯ 50
✯ your life	✯ comfortable	✯ screening	✯ colonoscopy
✯ cancer	✯ colorectal	✯ polyps	✯ sigmoidoscopy

That **left** Mrs. **Right's** husband, Mr. **Right**, who was not at all sure if _____ screening was **right** for him – he wondered if he would be **left** feeling _____. Mr. **Right**, said Mrs. **Right**, "The health care providers are professional and nice. They also gave me medicine to help me feel **right** _____."

Mrs. **Right** reminded Mr. **Right** that if everybody age _____ and older had a colonoscopy or sigmoidoscopy screening exam we could prevent almost all colorectal cancer by finding and removing polyps before they become cancer. Colorectal cancer can happen to anyone and often there are NO early _____.

Since Mr. **Right** wanted to stay healthy to teach his grandchildren the traditional ways, he decided there was nothing **left** to do but have a _____ to look at his rectum and all of his colon. During Mr. **Right's** colonoscopy the doctor removed a _____ (small growth). Mr. **Right** knew that colon cancer may develop from _____ in the colon, and colorectal cancer can be prevented by removing them.

Together Mrs. **Right** and Mr. **Right** are on the **right** road to good health. Listen up with your **right** ear and your **left** ear. The bottom line is colorectal screening can save your life. Don't be **left** out. Screening is **right** important to stay healthy. **Right** on!

✯ 40	✯ embarrassed	✯ family	✯ 50
✯ signs or symptoms	✯ comfortable	✯ screening	✯ colonoscopy
✯ cancer	✯ colorectal	✯ polyp	✯ sigmoidoscopy

Activity: BINGO

Play Bingo to discuss basic cancer words and recommended screening exams. Every person gets a BINGO card. Each BINGO card has all the answers but in a different order. Cut the list of questions apart so that each person can pick a question with the answer. Have participants read their question. After they read their question the other participants need to look at their BINGO sheet and find the answer. Participants call out the answer and the person who read the question says whether their answer is the correct one listed with the question. Once the correct answer is shared everyone can cross it off their BINGO sheet. When a person gets a straight, she or he can yell "BINGO" for fun. Play until all the questions have been asked and all the answers discussed. As participants share their question you can add to the information.

Play BINGO as a fun way to talk about cancer.

When possible include door prizes that support healthy, preventive messages about wellness and cancer prevention.

Bingo Questions

1. What is the name for more than 100 different diseases in which abnormal cells divide without order or control? **Cancer**

2. What do you call the spread of cancer from one part of the body to another part of the body? **Metastasis**

3. Tumors that are cancer are called what? **Malignant**

4. What virus causes almost all cervical cancer? **HPV**

5. How many servings of fruits and vegetables does a person need to eat every day to stay healthy and prevent cancer? **5 to 9**

6. 1200 people in the US die everyday from smoking or chewing this substance. **Tobacco**

7. This screening exam is important for both men and women. A sigmoidoscopy or colonoscopy every 5 -10 years beginning at age 50 helps to prevent what kind of cancer? **Colon cancer**

8. What is the name of the x-ray breast exam used to find abnormal breast changes? **Mammogram**

9. What is the biggest risk factor for breast cancer? **Being Female**

10. How often does a woman 40 years old and older need to have a mammogram? **Every year**

11. At what age does a woman need to start having her yearly mammogram? **Age 40**

12. Why is it important for people to have regular cancer screening exams? **To Stay Healthy. You are Important to your Family and Friends.**

13. Why do we recommend colorectal exams, testicular exams, pap tests, breast exams, and mammograms?
Early detection. It can save your life.

14. What can you do to decrease your risk of developing cancer?
Make Healthy Choices. (eat healthy Native foods, stay tobacco free, avoid alcohol, exercise, and have recommended screening tests).

15. Now that you have learned the importance of cancer screening, what is one thing you can do to decrease cancer deaths? **Tell a Friend.**

16. What cancer is the most common cancer in young men between the ages of 15 and 35? **Testicular cancer**

17. What is the name of the screening exam that finds abnormal cells in the cervix before they become cancer? **Pap test**

18. Who should have a colon cancer screening procedure?
Men and Women age 50 or older

19. Men after the age of 50 need to talk with their health care provider about a prostate screening exam that may include a rectal exam and a blood test called a what? **PSA**

20. A tumor that is not cancer is called what kind of tumor? **Benign**

21. This word means that all signs and symptoms of the disease cancer are gone, although cancer cells may remain hidden in the body. What is this word? **Remission**

22. What procedure is often the first step in treating a cancer? **Surgery**

23. This localized cancer treatment uses high-energy rays or locally implanted radiation to kill the cancer cells. What is this type of treatment called? **Radiation**

24. This systemic treatment of cancer with anticancer drugs or chemical agents is called what? **Chemotherapy**

25. This is where the cancer first develops. **Primary tumor site**

26. A cancer diagnosis is made by looking at a sample of tissue under a microscope. Taking a sample of tissues is called a what? **Biopsy**

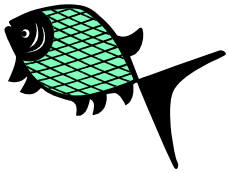
27. Describes how far the cancer has spread from the primary site to other parts of the body. **Stage of Cancer**

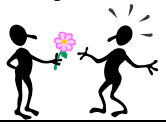
28. What is the word to help remember the 7 cancer warning signs? **C.A.U.T.I.O.N**

29. Researchers are looking for new types of cancer treatments and better methods of early detection. All of these things give us what for the future? **Hope**

30. The basic unit or building block of human tissue is called a what? **Cell**

B I N G O



cancer	**metastasis**	**C.A.U.T.I.O.N**	**PSA**	**remission**
5 to 9	**tobacco**	**chemotherapy**	**colon cancer**	**surgery**
mammogram	**Tell a Friend**	**being female**	**every year**	**radiation**
Make Healthy Choices	**Early Detection, It can save your life.**	***Stay Healthy. You are Important to your family and friends.*** 	**testicular cancer**	**age 40**
Pap test	**Men and Women age 50 or older**	**benign**	**HPV**	**primary tumor site**
Stage of Cancer	**Biopsy**	**Hope**	**Cell**	**Malignant**

Have Fun Learning about Ways to Stay Healthy and Prevent Cancer.

Colorectal Health Radio Show Activity

Give participants the following questions to ask as a caller and the answers to share as the expert. The facilitator reads the part of the announcer and asks for the next caller by number. The caller reads their question. Who ever has the answer on their paper reads it aloud.

Radio Announcer: Hello. Welcome to Wellness Ways Talk radio. Today we have with us several experts to talk about colon health and ways to prevent colorectal cancer. That's right colorectal cancer is almost 100% preventable. The telephone lines are open so call in with your colon health questions. Hello, hello, do I have caller #1.

Caller # 1 Wow! This is a really cool radio show. But…what the heck is colorectal cancer? I don't think I have a colorectal anything.

Expert: Thank you for calling. You are right, we don't have colorectals. However, both men and women have colons and rectums. The words colon and rectum are combined to make colorectal. Colorectal cancer means cancer of the colon or rectum.

Caller #2 Who gets colorectal cancer anyways?

Expert: Both men and women can get colorectal cancer. However, more than 90% of colorectal cancers are diagnosed in people who are age 50 or older.

Caller #3 Well I'm 50 years old, so you got me thinking. What causes colorectal cancer?

Expert: Well we don't really know what causes colorectal cancer.
The majority, about 75% of colorectal cancers happen in people with no known risk factors.

What we do know is that…colorectal cancer usually starts from polyps in the colon. A polyp is an abnormal growth inside the colon. Over time, some polyps can turn into cancer. Certain kinds of polyps called adenomatous polyps or adenomas are more likely to turn into cancer. It may take 5 to 10 years for a polyp to develop into cancer.

Caller #4 I heard that last expert talking about risk factors. What are the risk factors for colorectal cancer?

Expert: A cancer risk factor is anything that increases your chances of developing a specific kind of cancer. Having an increased risk doesn't mean that you will automatically develop cancer - it just means that you have an increased chance.

- ❒ Having a family history of colorectal cancer increases your risk for developing colorectal cancer**.** When we talk about family history, we mean having a first-

degree relative, like your mother, father, sister, brother, son, or daughter, who has had colorectal cancer. It is a good idea to learn if anyone in your family has had cancer and what kind of cancer and how old they were when they were diagnosed. Sometimes it is not easy to talk about cancer, but it is very important for your health.

- ❒ If you, yourself, had colon cancer, you have a greater risk of getting colon cancer again.
- ❒ Also if your bowels are always inflamed. Having chronic inflammatory bowel disease such as ulcerative colitis or Crohn's disease.

Caller #5 Taking care of my health has always been important to me. Is there anything I can do to decrease my risk of developing colorectal cancer?

Expert: Congratulations on taking care of your health. Good for you! These may be activities you are already doing. There are some choices you can make to decrease your risk of developing colorectal cancer. Just remember 4 things.

- ❒ Being physically active cuts your risk for developing colorectal cancer in half. It is as easy as doing 30 minutes of physical activity every day.
- ❒ Eating foods with lots of fiber like fruits, vegetables, and whole grains.
- ❒ Choosing to be tobacco free – your colon will love you! Tobacco use is highly associated with polyps that may develop into cancer. Choose not to chew tobacco. Avoid exposure to tobacco smoke.
- ❒ Having recommended colon screening exams to find and remove polyps before they become cancer.

Caller #6 My doctor told me that I should have colon screening. But I don't have any signs or symptoms so I thought I'd just wait until I had blood in my stool. What are the signs or symptoms of cancer of the colon or rectum any ways?

Expert: A lot of people, when they think of cancer, think of signs or symptoms. BUT there are <u>NO early signs or symptoms</u> of colorectal cancer! Don't wait for symptoms! It is good to have colon screening when you are healthy to stay healthy!

If NOT found early, colorectal cancer may cause signs or symptoms. Like

- ❒ Blood in or on your stool (bowel movement).
- ❒ Diarrhea, constipation or feeling like the bowel does not empty completely.
- ❒ Abdominal discomfort - frequent gas pains, bloating, fullness and/or cramping and you don't know why.
- ❒ Stools (bowel movements) that are thinner than usual. Change in shape.
- ❒ Constant tiredness.
- ❒ Losing weight and you don't know why.

These symptoms may also be caused by something other than cancer. The only way to know what is causing symptoms is to see your health care provider.

Caller # 7 Finally I got through! The phone lines have been really busy! Well what is the big deal anyway. Why is having a colonoscopy screening exam important?

Expert: Having a colonoscopy screening exam is important because it helps to PREVENT colorectal cancer by finding and removing polyps before they become cancer.

Caller # 8 Well I just turned 50. At what age should I begin to have a colorectal screening exam?

Expert: Happy Birthday to You…Happy Birthday to You..(Singing) Congratulations …You hit the colon screening jack pot. You are the magic age. Both men and women begin having a colorectal screening exam at age 50. If everybody started having colorectal screening exams at age 50, or younger if there is a family history of colorectal cancer, we could prevent almost all cancers of the colon and rectum. Now that's something worth celebrating!

Caller #9 I've heard a few stories about that colorectal exam…that I probably shouldn't repeat on day time talk radio. SO…how exactly is that exam done?

Expert: A trained health care provider uses a thin flexible, lighted tube to look in your colon. There are two types of recommended colorectal screening exams - either a sigmoidoscopy or a colonoscopy to find and remove polyps before they become cancer, and if there is colorectal cancer to find it early when it can best be treated.

Caller #10 What is a sigmoidoscopy (sig-moid-OSS-ko-pee)?

Expert:
A Sigmoidoscopy (sig-moid-OSS-ko-pee) is usually done every 5 years at a clinic or hospital. Before this test, you take a laxative to clean out the colon. For this test the health care provider puts a short, thin, flexible, lighted tube into your rectum and lower third of the colon or the descending colon.

Caller #11 I'm not sure if I can say this right…What is a *Colonoscopy* (ko-lon-OSS-ko-pee). So many big words.

Expert: A *Colonoscopy* (ko-lon-OSS-ko-pee) is usually done every 10 years at a clinic or hospital. Before this test, you take a laxative to clean out the colon. This test is similar to a sigmoidoscopy, except the health care provider uses a longer, thin, flexible, lighted tube to look for polyps inside the rectum and the ENTIRE colon.

- ❒ During the test you are given medicine to make you comfortable.
- ❒ The health care provider may remove polyps and small pieces of tissue or cells, called a biopsy, for closer examination.

Radio Announcer: Well it looks like we are out of time. That ends today's Wellness Ways Talk Show. A big round of applause to all our callers for asking such helpful questions for all of us to learn about colon health. Also it has been very helpful to have so many experts call in and share their knowledge about colon health. If you have more questions please talk to your health care provider to learn more about the ways you can take care of your health. Until next time this is Wellness Radio signing off.

Thank you for learning about cancer.

Please continue to ask questions and

learn new information.

Working together,

we will make a difference in the

story of cancer for American Indian people.

Live, Love, Laugh

2010