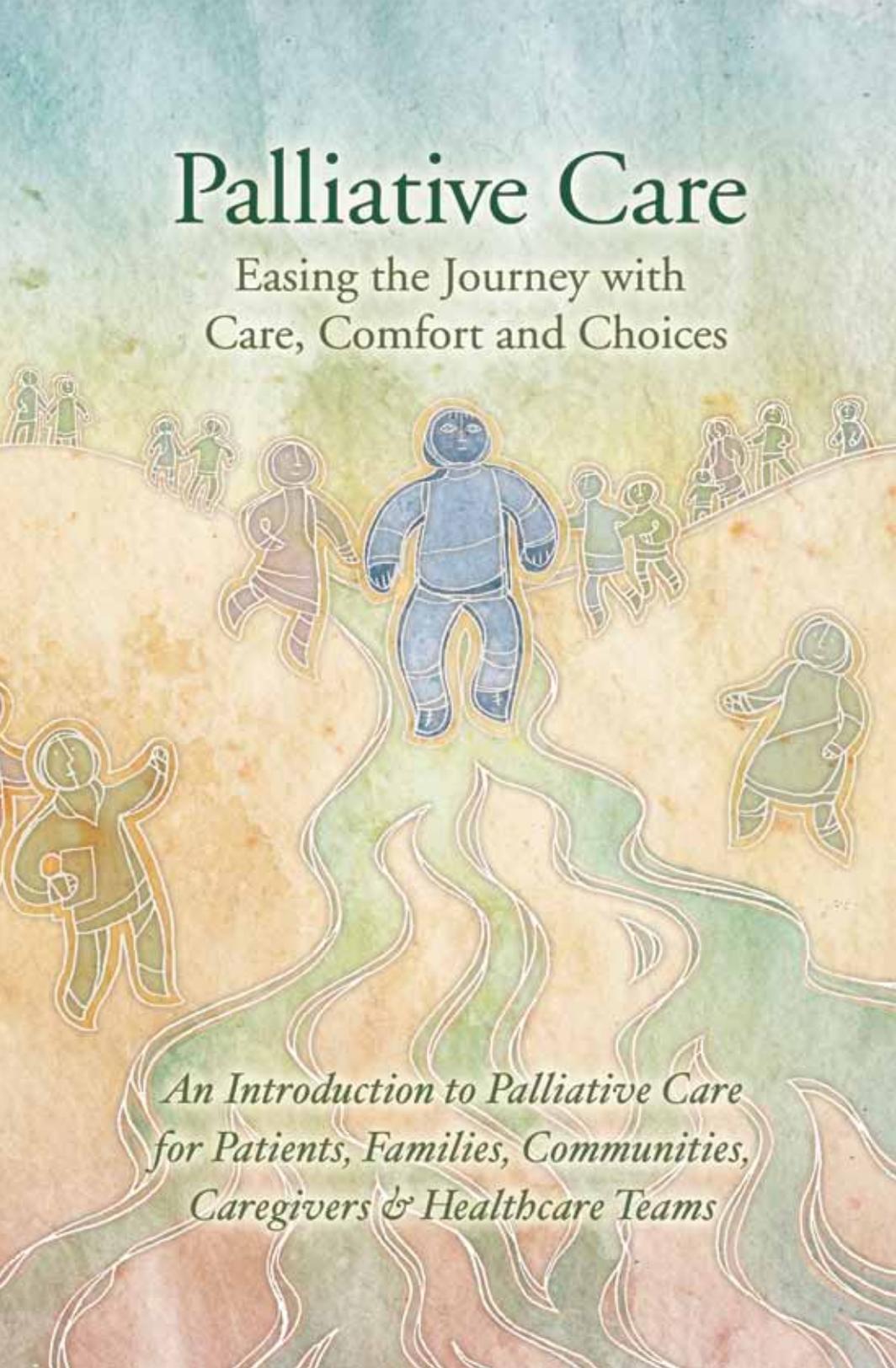


Palliative Care

Easing the Journey with
Care, Comfort and Choices

The background of the cover is a watercolor wash in shades of green, blue, and yellow. A white line winds across the page, forming a path that leads from the bottom towards the top. Along this path, several stylized human figures are depicted in various colors (blue, purple, green, brown). Some figures are walking, some are holding hands, and one is carrying a child. The overall style is soft and artistic, evoking a sense of a journey.

*An Introduction to Palliative Care
for Patients, Families, Communities,
Caregivers & Healthcare Teams*

*Thank you to the elders
and others who shared their
time, wisdom and stories.*

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Rita Blumenstein
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© Alaska Native Tribal Health Consortium Cancer Program, 2009

Written by Christine A. DeCourtney, MPA

Designed and illustrated by Dan Miller Graphics

Most of the stories and illustrations in this booklet are taken from experiences of the Alaska Native and American Indian people. However the palliative care message of care, comfort and choices is the same for all patients and families throughout the world.

Two worlds, one wish

LARS was born in a remote Alaska Native village in the 1920's. He did not speak English. He was drafted into the U.S. Army near the end of WWII but, for some reason, was then sent to a veteran's mental institution for 20 years. In the 1960's he went home to his village. Lars loved to read. He built boats, commercial fished and managed the utilities in the village. In his 70's he was sent to a nursing home in Anchorage to room with his brother who was diagnosed with dementia. He remained there after his brother died. As his 85th birthday neared he had one wish – he wanted to go home to his village and “have a cup of coffee.” He went to the hospital for emergency surgery. People from his village now living in the city came to visit. “It's so good to see people from home,” he said. Lars didn't go home for his cup of coffee. But he didn't die alone in the windowless nursing home room. He passed away peacefully at the hospital with sunshine streaming through the window.



JEAN was born in a small Canadian town in 1920. She married, had five children and moved to a large city. She loved reading, traveling and gardening. As the years passed, a doctor said it was too risky to do open heart surgery. It was time to contact Hospice. She was very upset. She said the doctors were “giving up” on her, “throwing her away.” The Hospice team came to see her and explained that they provide a different kind of care. Hospice helps people be comfortable and active when curative treatment is not an option, not just when death is near. As two years passed, Jean and the Hospice team grew to understand each other. She passed away gently at home in the spring, her favorite season of the year.



Two worlds, one wish – to be home and pass gently to the other side where Lars is enjoying a cup of coffee with longtime friends and my mother, Jean, is traveling the world pain free.

Christine A. DeCourtney

Christine A. DeCourtney

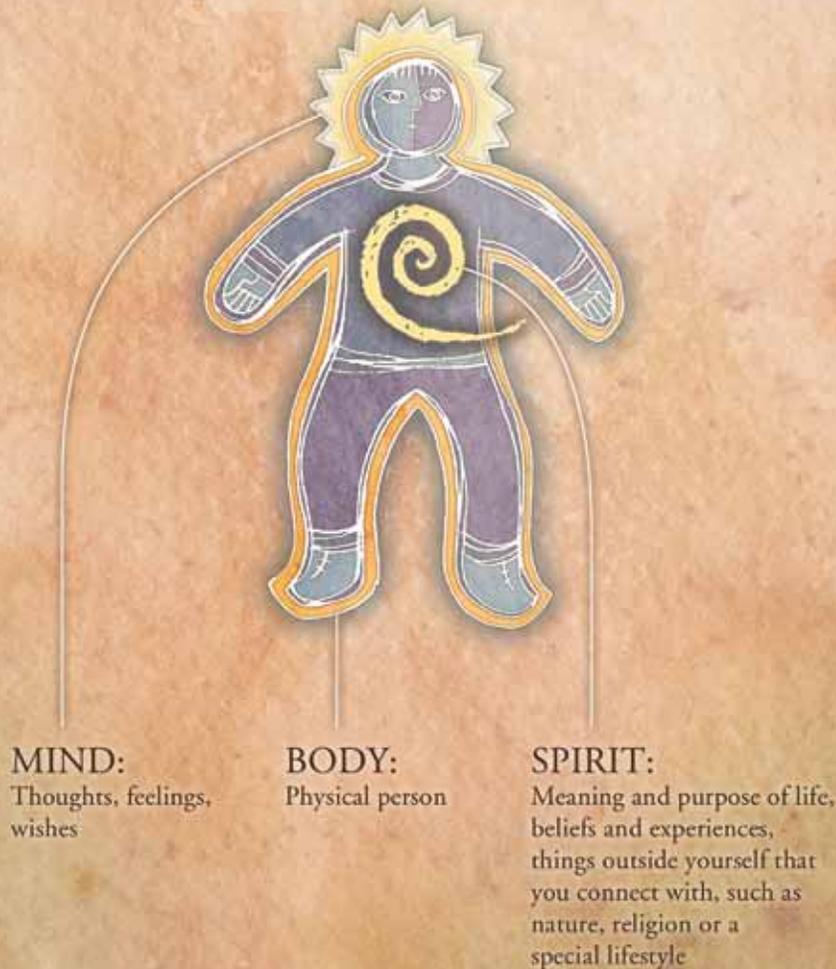


When someone is diagnosed with a disease like cancer, a long journey begins. The disease or illness may be treated and go away. It may go away and come back. In some cases the disease cannot be cured and the patient gets sicker. While a patient's body is treated and cared for to reduce pain and other symptoms, it is also important to care for the whole person at all steps of the disease journey. Palliative care pays attention to the mind, body and spirit of the patient and family. It begins with the diagnosis of a life-limiting disease.

PALLIATIVE CARE

Palliative care is care of the mind, body and spirit of someone diagnosed with a chronic disease like cancer. The family is also an important part of this care. Chronic diseases are sicknesses that generally can't be cured and may limit how long a person lives. However, people diagnosed with a chronic disease may live a long time through healthy lifestyle choices, medications and treatments even if there is no cure. Palliative care helps people live a meaningful and comfortable life when they have cancer or another chronic disease.

The mind, body and spirit are not separate. They are important parts of each person and impact health and well-being. Spiritual practices in American Indian and Alaska Native people generally include thanking the plants and animals that “gave themselves” so they could eat, thanking the soil that nourishes plants and animals, and honoring Mother Earth. Death is as natural as birth. It is not one's choice to be born or to die.



Care for the Body

- *Eating healthy foods is important for the body.*
- *Taking pain medicine can take away some kinds of body pain.*
- *Treatments like surgery, radiation and chemotherapy can reduce or take away painful tumors.*
- *When someone is nearing the end of life and not able to care for themselves, they may be admitted to a hospital.*

Care for the Mind & Spirit

- *Eating traditional and familiar foods is important for the mind and spirit.*
- *Taking pain medicine that lets a person stay awake and take part in activities they enjoy helps care for the mind and spirit.*
- *Recognizing the importance of traditional activities and scheduling treatments around the seasons or a special event help care for the mind and spirit.*
- *The healthcare team asks where the person wants to be and what is “home” to them. It might be the hospital, the nursing home, their own house in their community or a special hospice house. The healthcare team helps to find resources to get the person “home.”*

Palliative care is not limited to one location – it is a way of caring. It can be provided anywhere – hospitals, clinics, nursing homes, communities and homes. Palliative care combines the best of modern medicines and traditional remedies. It honors a person’s beliefs, lifestyle and practices.



“Our goal should be to help elders live out their lives in comfort, not taking medications they don’t need, and not living where they don’t want to live.” – Andrew Jimmie

Palliative Care and Hospice

Not long ago, people spent their whole lives living in the same community. Getting medical care was difficult and people often passed away at a young age. Families took care of elders in the communities where they had lived all of their lives.

As healthcare improved, people lived longer, but new health problems and “modern treatment” made it hard for someone to stay in the community when they were very sick. Elders passed away in unfamiliar surroundings, separated from family and lifelong traditions. People died in hospitals and nursing homes with many medicines and treatments to help them live longer, but it sometimes meant they were in pain and away from the life and people they loved. Trying to make people comfortable and as pain-free as possible was seen as “giving up.”

Palliative care is a different kind of care and just as important as “curing” care. When a disease cannot be cured, palliative care focuses on “healing” so people can live the rest of their lives as comfortable and as pain-free as possible.

Hospice care is a special kind of care for a patient and family when the end of life is near. It supports patient choices and continues to support the family after a loved one has crossed to the other side. Hospice agencies are available in large communities, but are not as available in small communities.



Hospice is part of palliative care. Hospice helps meet the special needs of people when curative treatment is no longer an option, and supports both patient and families.

“When it was my mother-in-law’s time, we went up river to see her. We took care of her all night, just giving her water. When she couldn’t drink water anymore, we dipped a goose feather in water and put it on her lips.”

– Alaska Native Elder

Honoring Cultures and Communities

“From the moment we are born, we begin our lifelong journey returning to the fetal position.” – Tribal Chief

Each person has a “culture” and a “community” with its own traditions, practices and beliefs. Each of us wants care that honors our way of life and beliefs. Common values include celebrating life, respect for traditional ways and hope for a peaceful passing to the other side in comfort and pain-free in familiar surroundings.

Palliative care embraces modern medicine’s pain and symptom management as well as including traditional medicine and spiritual healing.

In indigenous cultures like American Indians and Alaska Natives, death is a natural part of life, and it is important that beliefs are honored as death approaches. Palliative care supports these beliefs and traditions.

Healthcare teams care for people of many different cultures. Even though the healthcare team wants to be respectful and supportive, they may not know what are the important parts of a patient’s culture. Patients and families can help the healthcare team understand important traditional ways and rituals.

Remember, there is no perfect way to care. Be guided by your love for the person.



Traditions and values from different cultures:

- *Each year I wait for the first fresh salmon. It is sooo good!*
- *We always go to the cabin on the 4th of July.*
- *My son gets married in July and I need to be there.*
- *In our family, the eldest son must get important news first.*
- *Our whole family gathers when important news is coming.*
- *When someone is nearing the end of this life, it is important to open the window so the spirit can leave.*
- *I don't want to talk about dying, that means I may make it happen.*

What does the palliative care team need to know about MY culture?

Palliative Care and Children

It is especially hard when children are diagnosed with an illness that will not allow them to live a long life. Often treatment is long, hard and far from home. When continuing treatment will not make a child better and the side effects of treatments makes them feel sick, it is time for the family, with the help of the healthcare team, to make a difficult decision. Children often understand more about their disease than parents think they do. It is not necessary to share details with a child. It is more important to simply answer questions.

There are healthcare teams specially trained in palliative and hospice care for children. They help the family learn about choices for the best care and the best place to be for the remaining time in a child's life. An older child may be allowed to help make choices while taking into consideration the parents' wishes. For younger children, the parents must learn what is best for the child and where the family can be comfortable and get the most support.

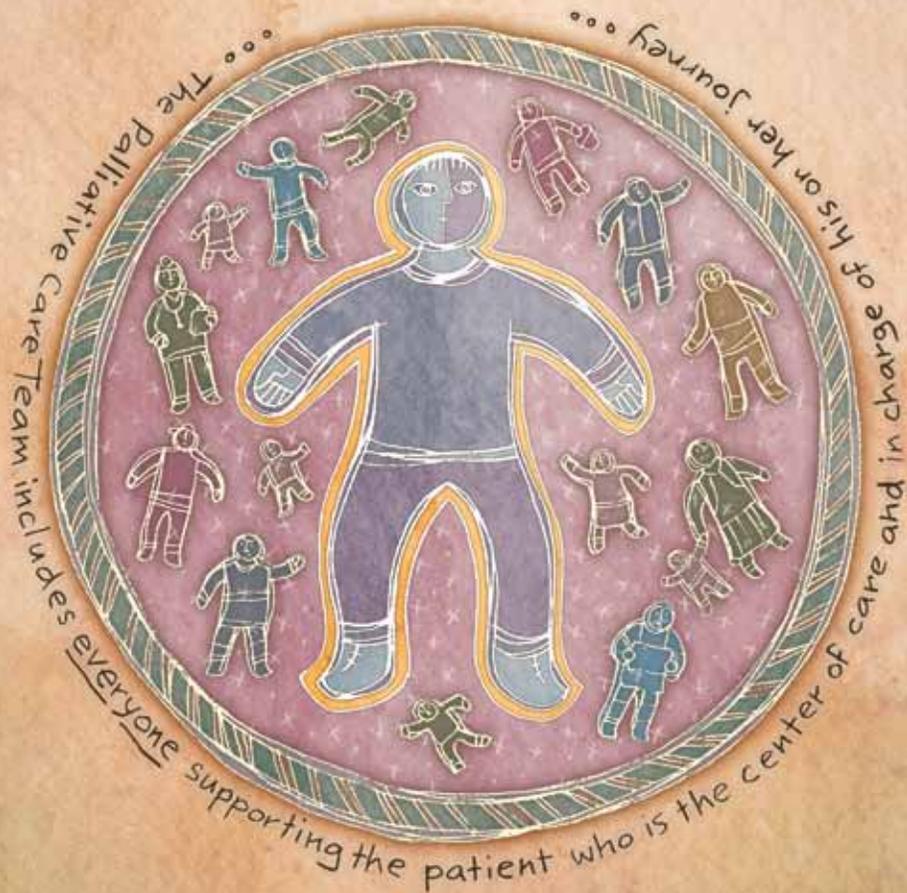
“We wanted to bring our child home to our village when we knew he wouldn't get better. We needed the support of our family and friends. But people in the village thought he would get better care at the hospital even though the doctor told us to take him home. We wanted to be home and he wanted to be home too, but we thought our friends would think we didn't want the best for our child.” – Parents of a dying child

- *Play brings happiness to children. Children should play every day.*
- *Sick children need to play too. If they are too weak to join in, they may still want to watch other children play.*
- *Encourage brothers, sisters and friends to play.*



“My body doesn't feel good on the outside, but on the inside my heart is singing.” – American Indian child

*Palliative Care –
It isn't about dying.
It's about living.*



The Different Stages of Palliative Care

Palliative care is important at all stages of a disease starting when a diagnosis is made, through treatment, survivorship and the end of life. While caring for the whole person is important at all disease stages, there are special things friends and families can do at each stage and things that are important at every stage of the disease.



Palliative care starts at diagnosis. Emphasis shifts from medical care to palliative care if and when the disease progresses.

It is not just the doctor and nurse who provide palliative care. The palliative care team includes everyone supporting the patient. It includes the healthcare team, family, friends, community members and many other people who care about the person diagnosed with the disease. Everyone can offer their own special support.

What patients can do at all stages

1. Decide who to tell, what to tell and when to tell people.
2. Allow yourself time to accept what is happening to you.
3. Help the healthcare team understand what is important to you.

What family and friends can do

1. Ask the patient if it is okay before you share information with others.
2. Ask "what can I do to help you?" not "Let me know if I can help you." Look and listen and then offer to do something specific if you notice a need.
3. Offer your presence. Listen. Honor the way the patient feels. It is okay not to know what to say. Be open. Be genuine. Sometimes talking is not needed.

Talking, visiting and supporting the patient, family and caregivers are very important at all stages of the disease.

“There is a sacredness in tears.

They are not the mark of weakness, but of power.

They speak more eloquently than ten thousand tongues.

They are messengers of overwhelming grief,

Of deep contribution, and unspeakable love.”

– Washington Irving



Palliative Care and Disease Diagnosis

When someone is diagnosed with a disease like cancer, it takes a while to understand and get used to the bad news of a diagnosis. Even though a doctor might tell a patient something, they might not remember it. Sometimes a person may want to talk about the diagnosis and sometimes they may not. Some people hide fear behind anger. Everyone is different. This is a very hard time.

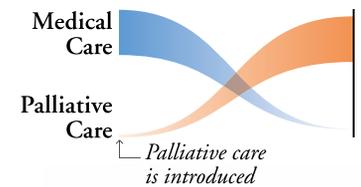
When someone is diagnosed with cancer there can be a need for many medical tests, decisions to make about the best kind of care, and how to take care of family. A person may go through many emotions like anger, sadness, depression or guilt.

What patients can do

1. Ask the healthcare team questions. Write down questions before your next appointment.
2. Have someone come with you to appointments to help hear what the doctor says.
3. Ask the healthcare team to schedule appointments and treatments around any activities that are important to you.
4. Let the healthcare team know what is important to your mind, body and spirit.

What family and friends can do

1. Be available to listen or visit, or just sit and stay close.
2. Offer to go to appointments.
3. Help take care of children so the patient and family can have time to make important decisions.
4. Make meals.
5. Offer to help find information.
6. Help decide who to tell and the best way to tell people.



David needed chemotherapy, but it was important to spend the summer fishing and hunting to support his family. His doctor understood the importance to his family and scheduled his chemotherapy after hunting season.

Ellen tried to understand when the doctor told her she had cancer. She wasn't ready to talk about different treatments and what they meant. The doctor scheduled an appointment to talk to her about her treatment at a later time.

How pain or “hurting” affects a person:

- *Pain is an individual experience and belongs to the person.*
- *Pain can be strong enough to make the person uncomfortable.*
- *Pain is what the person says it is and not what others think.*
- *Pain occurs where the person says it occurs, and it is as bad as the person says it is.*



Palliative Care and Treatment

Treatment for diseases like cancer may include surgery, chemotherapy and/or radiation. Treatment may make patients tired, not want to eat much and not want to exercise. They may or may not want to visit people or do some of the things they have always loved to do.



What patients can do

1. Ask questions. Write down questions before your next appointment.
2. Let the team know what is important to your body, mind and spirit.

What family and friends can do

1. Make special foods.
2. Visit during chemotherapy or after surgery.
3. Offer to run errands.
4. Share fish and berries.
5. Give children special attention.
6. Be available to listen.
7. Inform the healthcare team if you notice changes in behavior such as depression, weight gain/loss, and/or sleeplessness.

A young woman from a northern village came to Anchorage for cancer treatment. She was so scared that the doctor stopped chemotherapy. Staff arranged for her mother to come to Anchorage to support her. She finished treatment and went home.

Annie completed her daily rounds cleaning patient rooms. Some patients were in the hospital a long time and she saw them every day. One day she noticed a patient crying. She sat down and spoke to her in her own language. Then Annie sat and listened. She went out to tell the nurse that the patient was lonely and wanted to go home.

“Pain or ‘hurting’ is a many spoked wheel – if we know what is going on with a patient’s mind, body and spirit, we can take better care of the pain.”

– Greg G. Marino, DO, FACP

Palliative Care after Treatment Ends

When the signs and symptoms of a disease go away

When treatment is finished, a person may feel good that there is no sign of their disease. However, they may be very tired or have other side effects. It is also a scary feeling to be away from the healthcare team except for checkups after seeing the team so often during treatment. Every sign and symptom they feel might bring thoughts that the disease is back.



What patients can do

1. Tell people if you are too tired to visit.
2. Take care of yourself. Eat healthy food and exercise even if it is a short walk every day.
3. Take time to heal.
4. Even though treatment is finished, remember you may still have side effects. You have been through a long journey.

What family and friends can do

1. Help with chores.
2. Be available to listen.
3. Visit, but watch to see if they are too tired for company.

When **Nora** was diagnosed with cancer, she had to spend several months away from home getting treatment at a cancer center. She really missed her family, her community, her traditional foods and especially berries. After treatment ended, Nora returned home to a new job, her family and berry picking. Her husband built a new house for them.

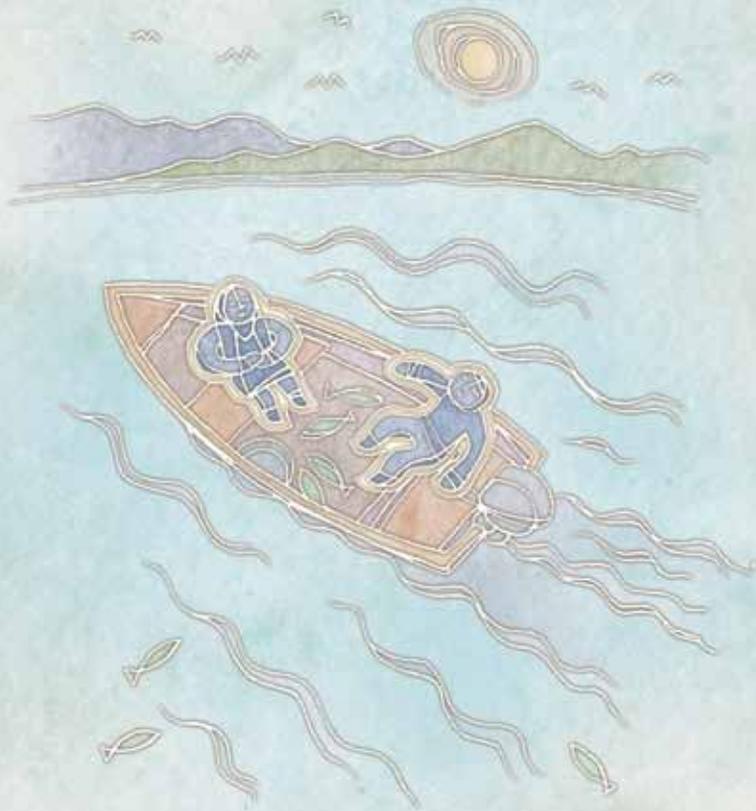
“I asked my grandmother what she needed. She told me to just sit down. I sat quietly and looked around. It was chilly and so I went outside and got wood for the stove. I thought she would like some tea. I made it and brought it to her.” – Elder sharing a childhood memory

Listening

“Our ancestors had many skills that we tend not to use because of technology. The skill of listening has always been with us. It is up to us to learn how to listen. Listening is part of our spirituality so that we can connect all parts of our being – mental, social, physical and spiritual.”

Listen so that you can hear a bird on the other side of the mountain take a sip of water.”

– Robbie Paul



Palliative Care after Treatment Ends

When the signs and symptoms of a disease don't go away, get worse or come back

When treatment is finished and the disease does not go away or comes back, it is a hard time for everyone. Treatment and care changes from a focus on curing the disease to using some of the same resources to make the person as pain-free and as comfortable as possible. **Palliative care is not giving up on a person!** It is a different kind of care. It helps the person enjoy the rest of their life doing many of the things they like to do.



The doctors told Nick he should stay in Anchorage because he had diabetes and heart disease, but he wanted to go home instead. Once home the visiting nurse asked him what he wanted to do. He said “I want to fish, hunt and gather berries.” With help, he fished by steering his boat to his fishing net and his wife pulled in the net. He used his walker as a gun rest to shoot a moose after it wandered into his yard. He also gathered berries. Nick passed away at home with his family by his side.

What patients can do

1. Think about what is important to you. Share this with the healthcare team, family and friends.
2. Make sure the healthcare team knows what is important to you including where you want to be for the last part of your life.
3. Be honest about your feelings and fears.
4. Enjoy each day.

What family and friends can do

1. Know that it is okay if a patient just wants to continue daily life.
2. Ask if there are special people you can help arrange a visit from or a trip to see.
3. Offer small acts of caring to the patient, family and caregivers, like a hug, a shoulder touch or a cup of coffee or tea.
4. Offer your quiet presence. Talking and “doing” isn't always important.

“Hope is being honest with yourself and positive about your future no matter how long it is.”

– Lance Armstrong Foundation

SHARING YOUR MEMORIES, THOUGHTS AND FEELINGS

THE PATIENT: It is difficult when you don't feel well and know you will not get much better. Not being able to go where you want to go or do what you want to do is hard. Side effects from a disease or medicine can make day-to-day life uncomfortable or painful. This is a time to think about what you want to share or tell family and friends. It is also time to think about some of the good things you have done and good times that you have had. When you spend time slowly thinking about the small details of a special memory or just something you love to do, it can help you relax and feel better.

There is no "right" way to share stories, memories or wishes. Ideas include:

- Keep a journal or log
- Make an audio tape of special memories that you want people to remember
- Record family stories on a video camera
- Ask a child or grandchild to write down your stories
- Invite a special friend or relative to come over regularly and record or write down family history

Ideas to help you remember and share memories, thoughts and wishes:

- What I want people to remember about me is . . .
- Some of the things I love to do are . . .
- I remember when I was a child . . .
- What you should know about our family . . .
- I never told you about . . .
- I wish that I . . .
- It is important for me to . . .



FAMILY AND FRIENDS: When someone you care about becomes sicker and sicker, it is hard to know what to do or say. Visiting, calling, or writing is still very important. This can be a very lonely time for someone who can't get outside or go places they like to go to whether it is picking up mail from the post office, going shopping, going to church, going fishing or just hanging out at the local coffee shop or restaurant.

Here are some ideas to help you plan a visit:

- Make a list of good times you shared. Bring it when you visit and leave a copy, or mail it if you can't visit.
- Bring a newspaper or magazine and read it to the patient so they can stay up-to-date with the news.
- Plan a visit when a special show is on television or radio so you can enjoy it together.
- Take digital pictures or video that show changes in the seasons, a school concert, basketball game or just hellos from friends.
- Bring a special food, tea or coffee to share (check with caregiver first to make sure it is okay).
- Bring a book, knitting or another project so you can sit near the patient when they don't want to talk.
- Tell a funny story. Laughing is good!

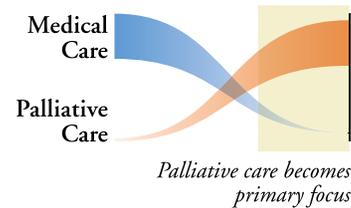
Ideas to start talking when you visit or call:

- The best time I had with you was when . . .
- Tell me a story about when you were little . . .
- I think of you when I eat . . .
- I will always remember . . .



Palliative Care as Life's End Nears

When someone learns that there are no treatments to make their disease go away or help them get better, it takes time to accept this fact. Just like when getting a disease diagnosis, a person may go through many emotions like anger, sadness, depression or guilt.



It is time to think about emotional and spiritual healing. It is time to reconnect with family and friends. It is important to think about many things including how and where to spend the remaining days. It is time to think about what is possible. It is important to identify resources to help make personal choices happen.

As a person gets sicker and less able to move around, they may speak or talk about having spoken to a loved one or friend who has already passed to the other side. The person is detaching from this life and is being prepared for the transition to the other side. This experience is real to the dying person and is normal and common.

“We are not human beings having a spiritual experience. We are spiritual beings having a human experience.” – Pierre Teilhard Dechardin

“I do not want to die a death of a thousand needles. There is no death – only a change of worlds. The goal is not to prevent death but to prevent unkindly and untimely death. Let me die with dignity, not pity.”

– Tribal Chief

What patients can do

1. Let the healthcare team and family know as soon as possible where you would like to spend the last part of your life.
2. Get important papers together such as pension and veteran's information.
3. Make sure special documents are completed that will let the healthcare team know your wishes if you can't speak for yourself.
4. Share traditions, beliefs and rituals that are an important part of your culture with the healthcare team. The team wants to be respectful and supportive.
5. Decide special things you want to do.
6. Think about what you want to say to family and friends.



What family and friends can do

1. Listen, comfort and be present. Words are not always needed.
2. The power of touch is comforting and healing. Learn what kind of touch is comforting to the patient, whether it is touching a shoulder or hand or giving a foot or back rub.
3. Do chores such as laundry, or help with childcare.
4. Visit the patient if they are in the hospital. If the patient is in another community you can also ask family or friends who live there to visit.
5. Help the patient to do as many things in as normal a way as possible.
6. Honor rituals and traditions.
7. Try not to feel guilty that you are living and they are dying.
8. Take care of yourself—if you don't take care of yourself, you can't take care of someone else for very long.
9. Support the main person providing care. Offer to let them go for a walk while you sit with the patient, or just give them a chance to talk.

The Agony of Your Grief

*“I share with you the agony of your grief,
The anguish of your heart finds echo in my own.
I know I cannot enter all you feel
Nor bear with you the burden of your pain;
I can but offer what my love does give:
The strength of caring,
The warmth of one who seeks to understand
The silent storm-swept barrenness of so great a loss.
This I do in quiet ways,
That on your lonely path
You may not walk alone.”*

– Howard Thurman



Grief and Mourning

Grief is a natural human reaction that comes as we anticipate and adjust to the changes caused by the loss of someone important to us. It can be felt physically, mentally and spiritually.

Mourning is the expression of our grief. How, when and how long a person grieves is different for everyone. There are different kinds of grief. Anticipatory grief or grief when a person hasn't yet died is one kind. It can happen to the person with the disease, family members or friends. After a person dies, the healthcare team, family and friends mourn the loss.

It is important for everyone to take time to grieve, the healthcare team as well as family and friends. Providing good palliative and hospice care means learning to understand the needs and wishes of someone's mind, body and spirit. In doing so we become close to a person. It can be hard when they pass to the other side. Remember that you gave them the gift of yourself. Honor the loss that you feel.

What family and friends can do

1. Listen and comfort.
2. Visit. It is hard to be alone sometimes.
3. Bring special comfort foods.
4. Offer to take the family to gather berries or on other outings.
5. Talk to children. Pay close attention to what they say. Sometimes children think they did something wrong to make the person die.
6. Remember the hardest time for family members can be months after the death or on special days like birthdays, holidays and anniversaries.
7. You cannot take away the pain, but with your support and presence, you can help the healing begin.

*“Over there, our spirit is going. It is good.
I am going over there. I am happy to go over there.
The sun is going down. It is good. Over there, I
will be reborn. From the hoot of the owl I will fly.”*

– Rupert Encinas, Tohono O'odham

Community Palliative Care for Someone Nearing the End of Life

Many people nearing the end of life want to be with family and friends in comfortable surroundings. The smell of the sea, bird songs, views from the window, creaking floors can be comforting. The feeling of “home” is what is important. It is different for everyone depending on lifestyles and family history. Being “home” can help provide comfort and symptom relief. Not all people want to or can go home. Some people feel more comfortable in a hospital or with the resources of a big city. But it is possible to help make the “feeling” of being home closer by providing support and small acts of caring to the patient and family.

When a person wants to go home, every effort should be made to help them get their wish. The sooner the healthcare team and community know this decision, the more likely that a plan can be made to help the patient go home.

There are resources in every community. They differ depending on the size of the community, what medical and social services are available, and the needs of the person. There must be someone who will be the “primary caregiver” who will commit to being with the patient most of the time except when other help is available. If there is no primary caregiver, it doesn't matter if the person lives in a big city or the smallest village—they must stay in a place that is safe and where help is available.

It is important that members of a community become part of the palliative care team as soon as possible when someone makes a decision to go home. This can include the church, tribal council, city or town council, schools, families and other groups. Working together, the team can look for resources through federal, state, local and nonprofit agencies to help find equipment such as a hospital bed or help make the house more accessible for a wheelchair.

While large cities may have less of a “community” feel, there are still churches, schools, volunteer organizations, and other groups and individuals that want to help. For instance, when people live in apartments and don't know each other very well, many people are still willing to help someone nearing the end of life and their family by providing a meal or running errands.



Community Caring

When a community gets together to help care for a patient and family, they do it because they want to offer support and help during a difficult time. This is very important for the patient and family and can make a big difference as to whether or not the patient can come home. While everyone wants to offer support, sometimes it is not what the patient or family needs at a particular time.

Jesse lived in a village with no running water. He spent part of every day getting water. When he was diagnosed with cancer and there were no more treatments, he came home. Jesse was too tired to get water. Friends in his village helped make sure his house had fresh water every day.

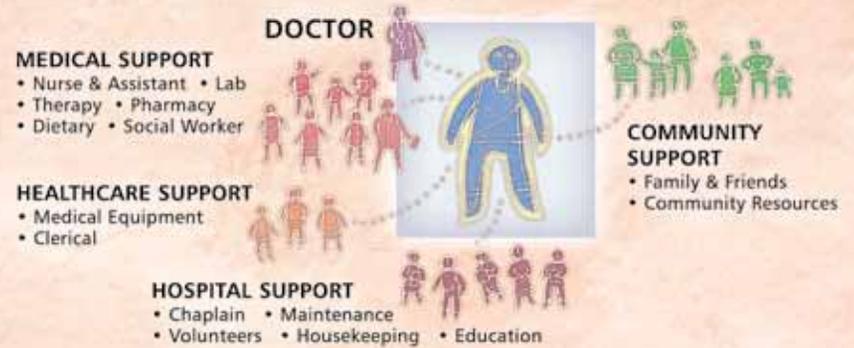
It is important that there is community leadership to oversee and organize the support. The leadership can be one person or several, and the role can rotate or change. Leadership can help figure out what is best for everyone, help avoid hurt feelings and make sure the family has the best help possible. They can solve problems as they come up and help everyone support each other during this time. Planning for how the community will respond to unexpected changes is also important.

Share the Care, How to Organize a Group to Care for Someone Who is Seriously Ill is a good book that gives ideas for how a community can plan the best way to support someone who is nearing the end of life and their family. It is in many bookstores or can be ordered through the Internet.

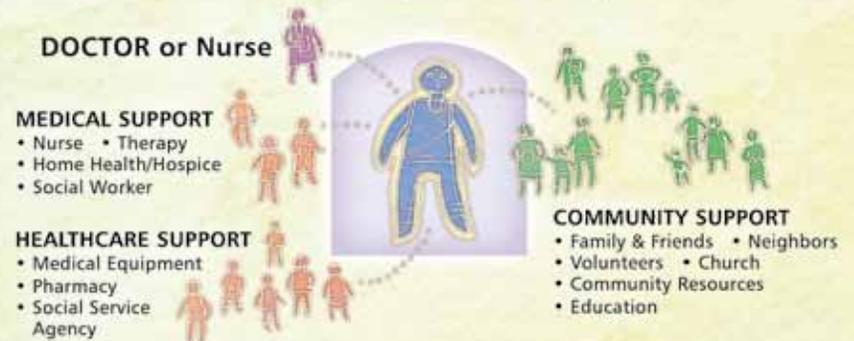
The first step in community planning is to determine what you have, not what you don't have.



Palliative Care in a hospital



Palliative Care at home in a city



Palliative Care at home in a village



RESOURCES

BOOKS

Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying by Maggie Callanan R.N. A practical guide for bringing care and comfort at the end of life.

Kitchen Table Wisdom: Stories That Heal by Rachel Naomi Remen. Sharing of real-life stories about suffering, meaning, love and faith.

Handbook for Mortals: Guidance for People Facing Serious Illness by Joanne Lynn and Joan Harrold. For caregivers as well as patients – topics include pain management, giving and receiving forgiveness, and suggestions for hard family conversations.

Share the Care: How to Organize a Group to Care for Someone who is Seriously Ill (book, workbook, and video available) by Cappy Capossela and Sheila Warnock. Guidelines for lay people to develop a unique caregiver support system for elders, family or friends facing a serious life threatening illness or injury. www.sharethecare.org

LiveStrong Guidebook by Lance Armstrong Foundation. Resource for cancer survivors, loved ones and caregivers from the time of diagnosis through cancer treatment and beyond. www.livestrong.org

ORGANIZATIONS

CancerCare

A national nonprofit organization that provides free professional support services for anyone affected by cancer. www.cancer.org
1.800.813.HOPE

Caring Connections

A national consumer engagement initiative to improve care at the end of life. www.CaringInfo.org

American Cancer Society

www.cancer.org, 1.800.227.2345

National Cancer Institute

www.cancer.gov, 1.800.4.CANCER

Alaska Native Tribal Health Consortium

www.anthc.org, 907.729.1900

Alaska Native Medical Center

www.anmc.org, 907.563.2662



PALLIATIVE CARE

*Easing the journey with care,
comfort and choices*

CARE

Nick knew his cancer had spread to his back. He was in a lot of pain. He knew he wasn't going to be cured from the cancer. His doctor sent him to radiation treatment to help make the tumors smaller so he wouldn't be in as much pain.

COMFORT

John worked at the hospital in the maintenance department. While he was changing a light bulb in a patient's room, he learned that the patient was from his village and had been in the hospital for a long time.

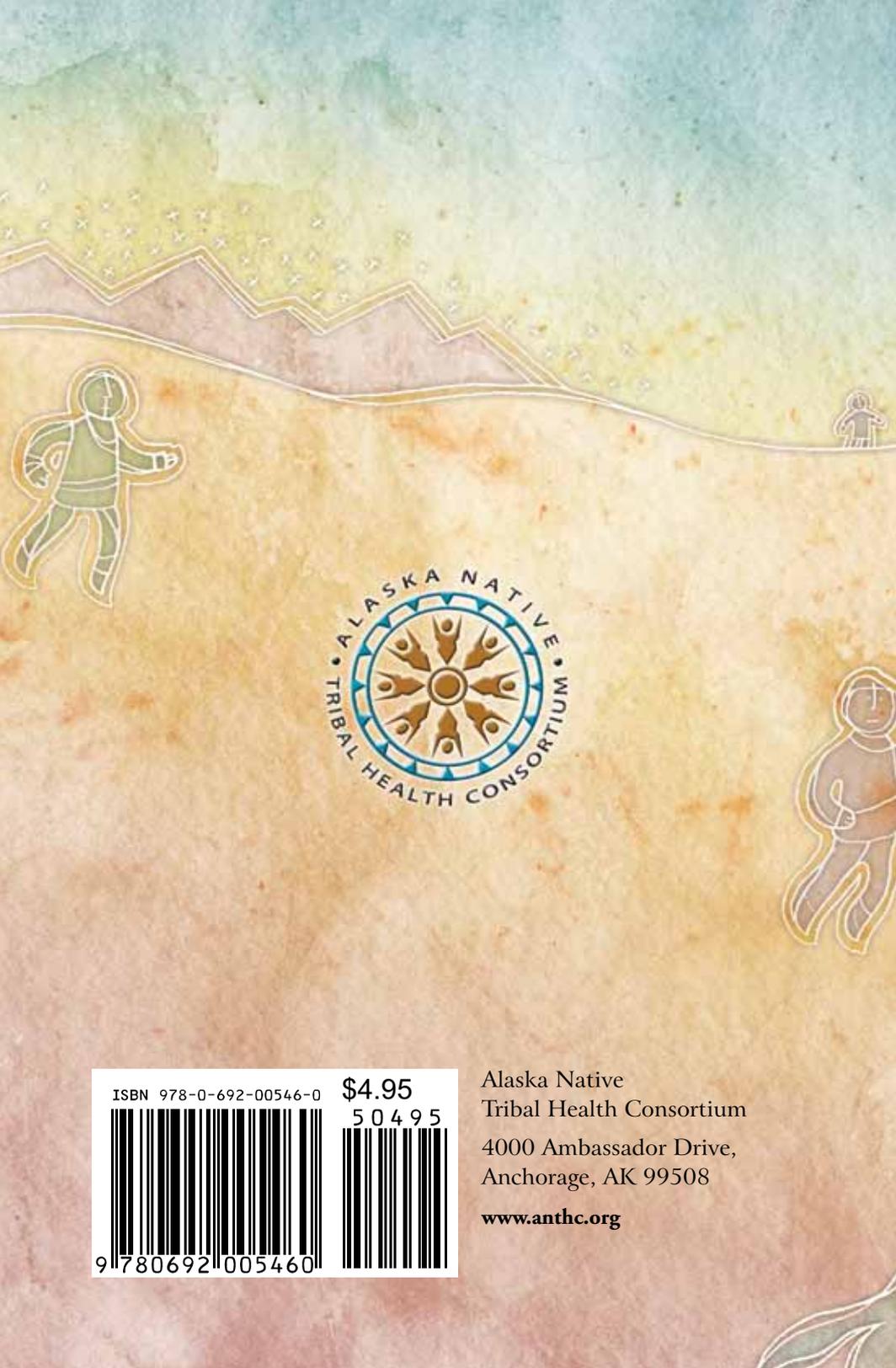
After talking to the nurse to make sure that it was okay, he brought a bowl of fish soup and news about the people in the village to the patient.

CHOICES

Tom had lived most of his adult life in a remote cabin in northern Canada. He fished, hunted and trapped.

He never married. He was diagnosed with stomach cancer. A visiting nurse came to see him once in awhile. As he got sicker, she asked him if he wanted to come to the hospice house in the city. He decided that he wanted to remain alone and die in his cabin which he had built. It was the only home he knew.

The nurse came to see him again. This time he was very upset and wanted to go to the hospice house. A bear had started prowling around his cabin. Tom was okay when he had made the decision to die alone. But he was determined that a bear was not going to make the decision about when and how he died.



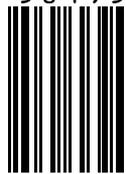
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