

**FIRST NATIONS**

**CARING FOR**

**THE TERMINALLY ILL**

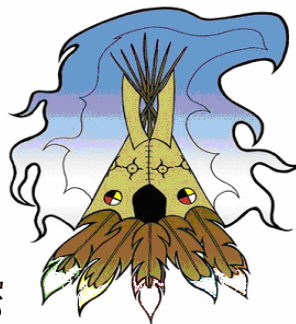
**HONOURING THE CHOICES**

**OF THE PEOPLE**

**PERSON/FAMILY/COMMUNITY**



Caring for the terminally ill



Choices of the people



# Palliative Care

To cure sometimes,

To relieve often,

To comfort always





# Collaborators

**We would like to honour the memory and contributions of Jim  
Boshkaykin – Seine River First Nation**

## **Support People:**

Teresa Trainer  
Diane Longboat  
Jane Harty  
Archie Hyacinthe  
Rick Petawanickweb

## **Reviewers:**

The group gratefully acknowledges the following people for their assistance in reviewing the manual and providing valuable information and feedback. They have agreed that the information is an important component of Palliative Care for First Nations:

Rosella Kinshameg – Wikwemikong Unceded Nation  
Dorothy Medicine – Rainy River First Nation  
Annie Wilson – Rainy River First Nation  
Bessie Mainville – Couchiching First Nation  
Josephine Potson, Gzhewaadiziwin Health Access Centre  
Veronica Fobister, Kenora Chiefs Advisory  
Jane Harty, Kenora Area Health Access Centre  
Diane Longboat, Six Nations  
Esme Boone, Kenora Area Health Access Centre  
Archie Hyacinthe, Kenora Area Health Access Centre  
Rick Petawanickweb, Kenora Area Health Access Centre  
Randy White, Kenora Area Health Access Centre  
Rose Marie Allen, Elder  
Walter Redsky, Elder  
Jim Boshkaykin, Elder  
Lillian Boshkaykin, Elder  
Mary Nelson, Elder  
Sarah Strong, Elder  
Ella Dawn Green, Elder  
Nora White, Elder  
Workshop Working Group National Palliative Care Conference (Quebec City)  
First Nations and Inuit Health Branch, Home and Care Program

**Artists:** Esme Boone, Rachel Kovachis

**E-mail address – [cathy.randus@tb.ccac-ont.ca](mailto:cathy.randus@tb.ccac-ont.ca)**

**1-800 contact number – 1-800-626-5406**

# Team Members

- Barb Linkewich: North Western Ontario –Program Manager  
for the Pain & Symptom Management Team  
(807) 343-1625
- Josephine Potson: Gizhewaadiziwin Health Access Centre -  
Traditional Healing coordinator, (807) 274-  
3131
- Veronica Fobister: Kenora Region – Program Manager of the  
Long Term Care Program for Kenora Chiefs  
Advisory (807) 467-8144
- Wilma Sletmoen : Kenora Rainy-River CCAC  
(807) 274-2343

## **Printing support provided by:**

Northern Education Centre for Aging and Health  
Kenora Chiefs Advisory Home and Community Care  
Pain & Symptom Management Team

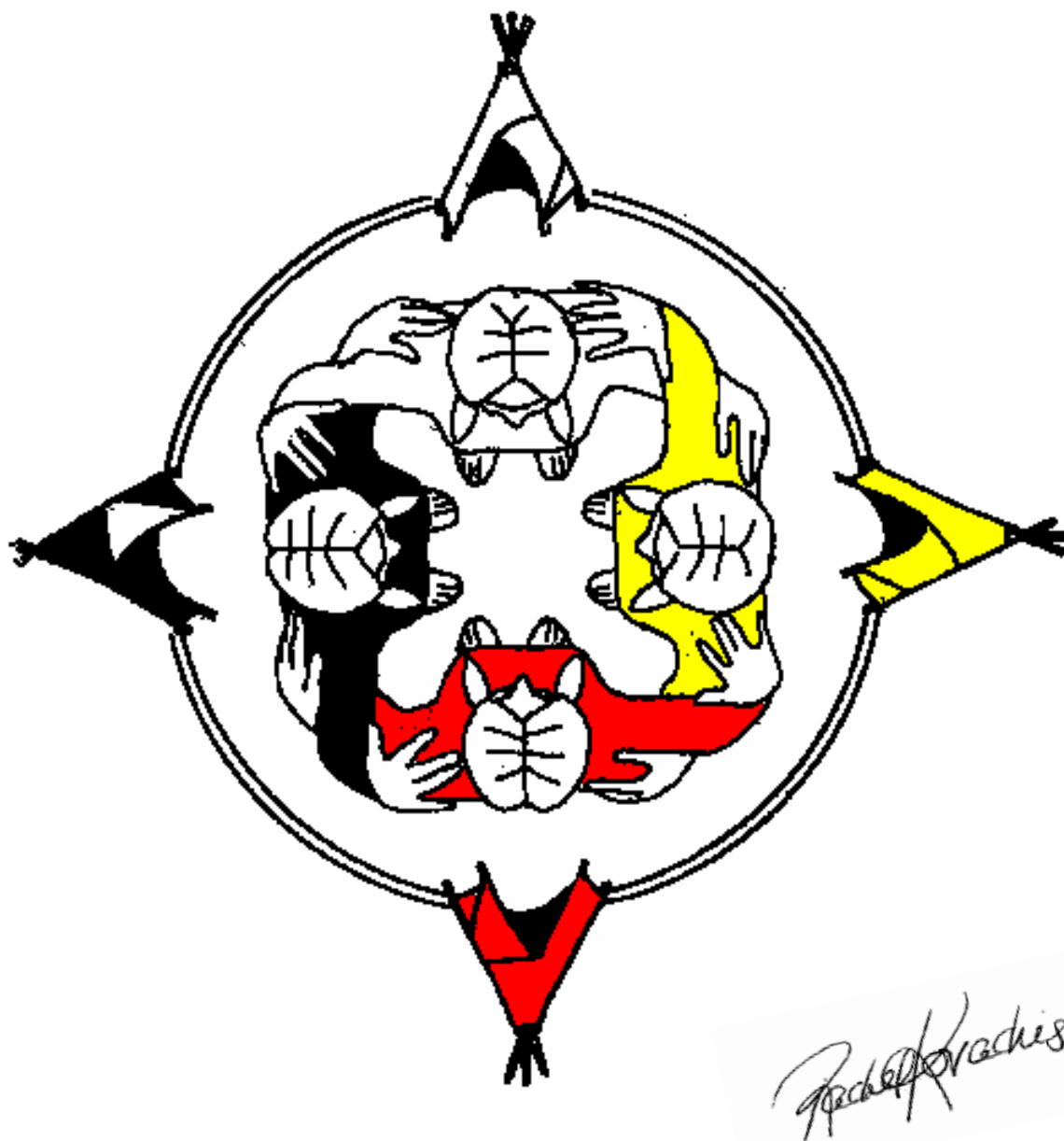
## **Design Support:**

Cathy Randus  
Rose-Anne Fournier  
Fiona Skogstead  
Leah Schouten  
Sue Klass  
Sonya Murray

2003

# Nii win ikwe-wag mazina'igan

(Four Women Book)



Rachel Kovachis

This book is designed to support aboriginal people and their caregivers in rural and remote communities living with life threatening illness. It is a small-budget project created through collaboration and good will for the free use of anyone who may benefit from it. We simply ask that you acknowledge our work by honouring the following guidelines: Permission to copy book in total, including lists of authors, contributors, and acknowledgments is granted. Permission is also granted to reproduce any part of the book, provided a credit to the source is placed on every page. The four women hope the booklet will help you with this important work of caring for people at the end of life.

**2<sup>nd</sup> edition – July 2006**

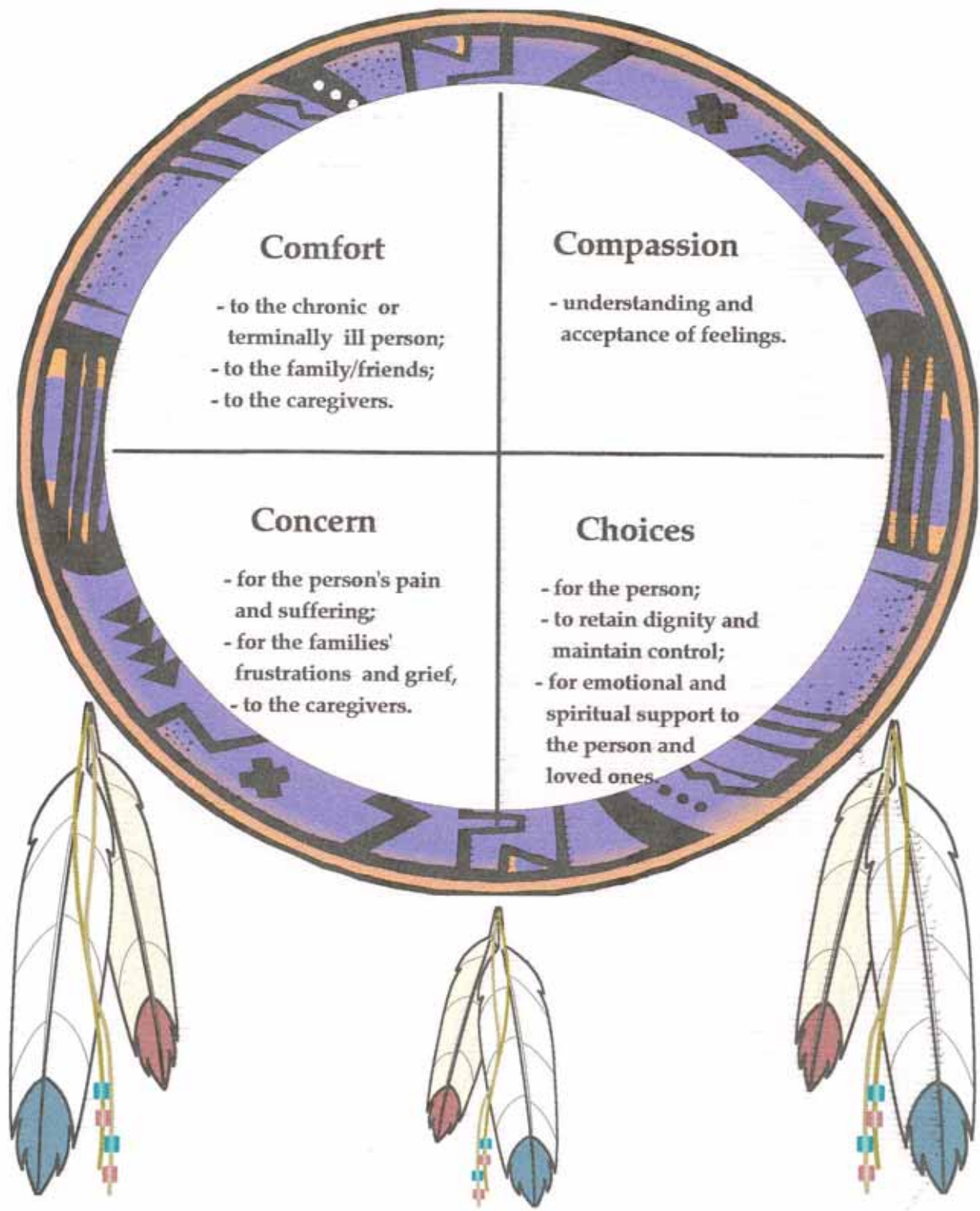
## Table of Contents

<b>Palliative Care Offers.....</b>	<b>10</b>
<b>The Terminally Ill Person's Experience.....</b>	<b>11</b>
Body Changes .....	12
Caring for Loved Ones at Home.....	13-18
Personal Care.....	19-32
Bed Care.....	33-37
Not Feeling Hunger, Not Eating Much.....	38-46
Difficulty in Breathing.....	47
Skin Problems.....	48-49
Feeling Weak.....	50
Constipation.....	51-52
Not Sleeping Well and Feeling Tired.....	53
Pain.....	55-61
Exercises.....	62-64
Care for the Social and Emotional Aspect .....	65-70
Care for the Spiritual Aspect.....	71-74
Aboriginal Customs.....	75-89
When Death is Near.....	90-98
Grief.....	100-109
Finding your Community Care Team .....	110-123
References.....	124
Resources.....	126-142





# PALLIATIVE CARE OFFERS:



# THE TERMINALLY ILL PERSON'S EXPERIENCE

A terminally ill person has to face a number of changes, which include:

- Physical changes in their body
- Spiritual changes in the way they think about their future and their spiritual needs
- Social changes and emotional changes
  - In their independence
  - In their abilities
  - In their relationships with others



# Body Changes

You may notice several body changes in the person who is terminally ill. The next pages list the most common and give some suggestions to help.



# CARING FOR LOVED ONES AT HOME

BY HARRY VAN BOMMEL (AUTHORIZED)



## General Guidelines:

When providing personal care, the caregiver should allow the terminally ill person to maintain a sense of:

- Dignity
- Privacy
- Control

## What to do:

- Visit first, recall day's events, establish caring relationship, laugh together
- Men work better caring for other men – women with women
- Check the person's emotional state before starting any work with them
- Be sensitive to what the person is feeling
- Offer reassurance
- Explain what you are going to do to help the person
- Develop a comfortable rapport
- Involve the person in decisions around his/her care
- Ensure privacy by closing the door
- Remove sick room items like bed pans from sight when not in use

There are some special care requirements when a person is unable to get out of bed that they might need help with.

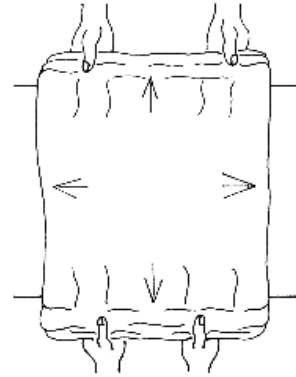
## Helping People to Get Around

A good deal of your time may be spent helping the person get in or out of bed, walking around their home or helping them get to their bathroom. You have seen relatively short nurses help people around the hospital so you know that you do not need to be very tall or physically strong. You do need to be smart about what you do so that you do not hurt yourself. Ask your visiting home nurse for tips -- they are the experts. Here are some specific tips that might help as well:

- Keep your feet and toes pointed straight ahead with your weight evenly divided on both feet.
- You need to stand as straight as you can, keep your head up, shoulders down and knees slightly bent.
- When lifting someone, you should have your head, shoulders and hips form a straight line. You need to bend your knees and keep your back as straight as possible when lifting. Have your feet about 30 cm (one foot) apart for best stability.
- Learn a few stretching exercises for your legs, arms, back and stomach muscles and practice them before you do any lifting or assisting.
- The closer you are to the person or object you are lifting, the less strain on your muscles.
- Make sure the area you will be lifting or walking in does not have anything in the way (e.g. children's toys, throw rugs) and that it is not slippery.
- Wear comfortable, low heel shoes and loose fitting clothes.

## Moving Someone in Bed Using a Drawsheet

The greatest invention in the world (or so it seemed to me at the time I was taking care of my parents) is a draw sheet. This is just a regular sheet folded several times and placed side-ways on the bed. The



person lies on top with the sheet under their shoulders and hips. With a person on either side of the bed,<sup>1</sup> each grabs the sheet at the same time and together they can lift the person up to move them closer to the head or the foot of the bed. This is very helpful when someone is sitting up in bed and they keep sliding to the foot of the bed. If they cannot move themselves, the draw sheet is perfect to move them without a lot of pulling or pushing on their skin. You can also use the draw sheet to help turn someone onto their side by placing one end of the draw sheet over the person and pulling it towards you.

## Helping Turn Someone in Bed

Other than the draw sheet, you can also help a person turn in bed in the following way:

1. Have their far arm across their chest towards you.<sup>2</sup>

2. Bend the far leg at the knee while their foot still rests on the mattress. Bring the bent leg towards you.<sup>3</sup> As you do this, their far shoulder will naturally start to move towards you through the leverage of the leg. Reach over with your hand to guide their



<sup>1</sup> Editor's Note: Roll the sides of the sheet closer toward the person's side, grab the roll and lift.

<sup>2</sup> Editor's Note: You should also bring the arm nearest you straight out at shoulder level.

<sup>3</sup> Editor's Note: Place your hand on the knee farthest from you and pull the bent knee towards you.

shoulder towards you comfortably and safely. This will put the person on their side with their bent knee giving extra security.

3. Place pillows to support their back and, if necessary, between their legs for added comfort. Adjust the head pillow as needed.

## **Getting Someone Out of Bed and into a Chair**

1. Put a safe and solid chair with arm rests next to the bed facing you. The chair should be high enough to make it easy for the person to get into it and out again.
2. Raise the head of the bed as high as it will go.



- Help move the person's legs over the side of the bed. Give them a moment to rest, as they may be a bit dizzy at first sitting up after lying down so long.
3. Help the person put on their slippers or shoes (or do it when they are still lying down if they cannot help).
  4. If the bed is too high, put a strong footrest by the bed to help the person step down comfortably.<sup>1</sup>
  5. Help the person slide forward to the edge of the bed so their feet are touching the floor of footstool.
  6. Face the person with your foot that is nearest the chair one step behind the other. This will allow you to turn easily in the direction of the chair.
  7. Have the person brace themselves with their hands around your elbows while your hands hold them under their elbows for leverage.

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<sup>1</sup> Editor's Note: Or remove the caster / feet to lower the bed.



8. Help the person slide off the bed.
9. Bend your knees and press your forward knee against the outside of the person's opposite knee. Let them catch their breath and balance themselves as they stand.
10. Let the person shuffle back ward towards the chair, if they can, and help them lower themselves. If they need help, pivot them using the pressure on their knee, and then lower them into the chair.

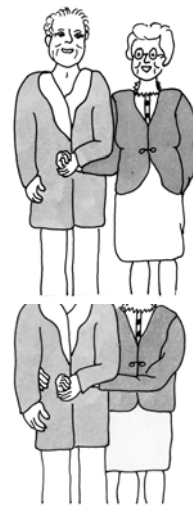
## **From a Chair into Bed**

Reverse the instructions from above making sure the person helps with as much of the moving as possible. As well, make sure the chair, foot stool and bed won't move while you are helping the person

## **Walking**

Help the person stand (as above) from their bed or a chair. You can offer extra support either by holding them under their arm or elbow.<sup>1</sup>

When you walk together, have your closest arm around their waist and the other hand can hold their nearest elbow or hand for extra support. Stay close to the person so that your hip can give them extra stability.



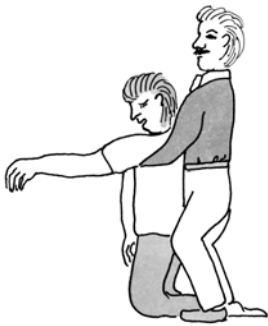
## **NOTE**

If the person can no longer stand and they begin to slowly slump onto the floor, bend your own knees and help them glide against your body and down your knee to the floor. After they have rested, you can put a chair in front of

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<sup>1</sup> Editor's Note: Let them hold you under their arm or elbow.

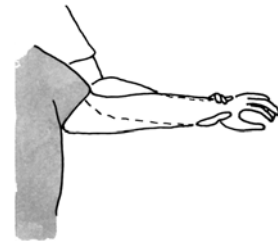
them and help them kneel in front of it for support as you slowly bring them to a standing position. Let them rest one hand on the chair with which they will push themselves up.<sup>1</sup> Put your strongest forearm under their bent free forearm. Bend at the knees and try to keep your back in good alignment



(although this is a difficult in this position). Lift up with your arm at the same time the person pushes up from the chair. Turn them slowly so that they can sit down in the chair for a more comfortable rest. If they cannot get up, wait for help to bring them back to bed or try to slide the chair to the bed. At all times, remember to safeguard your

own back since you will not be at all helpful if you injure yourself.

If the person is too weak to use both hands to push themselves up from the ground, have them use one hand on the chair and you use your strongest forearm under their remaining bent forearm. As they lift up from the ground using their bent pivot leg, you lift with your arm at the same time with your other arm providing support at their belt or around their waist



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<sup>1</sup> Editor's Note: Assist them to a standing position by having them rest one hand on the chair and also have them bring one knee up so that they are kneeling on one knee.

## **PERSONAL CARE**

### **Using a Bedpan or Urinal**

None of us enjoy having to use a bedpan or urinal. No matter how hard we try, it is an unnatural feeling and not all that comfortable. However, it is necessary sometimes. After you have helped the person with the equipment, give them some privacy and wait for them to call you for help again. Leave a clean bedpan or urinal and toilet paper close to the bed so that people, who are able, can use it themselves and just call you when they are done.

#### Specific Tips

Find out if they can use a commode beside the bed. A commode is a portable toilet that looks like a chair. It will allow many people to go to the toilet without them having to travel far. There are various types including ones on wheels and ones with removable arms. Your visiting home nurse, Home Care Case Manager, or family doctor can help you decide which is best.

#### NOTE

People who are receiving narcotic pain medication may have difficulty with bowel functions (especially with constipation). Any difficulties should be reported to one's family doctor or visiting home nurse immediately to prevent the problem from getting worse. People need to continue using the right dose of pain medication so that they can remain relatively pain free and alert but they also need help controlling any side effects of that medication.

If they cannot use a commode, follow these tips:

- Make sure you get the right kind of bedpan or urinal. There are different models for different purposes and you should get the kind that is most comfortable for you specific purpose.
- Make sure the bedpan or urinal is clean, warm (you can rinse it with hot water), and dry.
- Wash your hands thoroughly and dry them with a clean towel.
- You may want to put some talcum powder on the top of the bedpan so it doesn't stick to a person's skin.
- Once they are on the bedpan or urinal, you can raise the head of the bed to help them feel more comfortable. Make sure the foot of the bed is down so that urine will run into the urinal and not pour out by mistake.
- Make sure the person is wiped clean and dry.
- Cover bedpan or urinal before removing to prevent spilling. Empty in the toilet and clean. If you rinse with cold water and baking soda it helps keep the equipment odor free.
- Wash your hands and help the person to wash theirs.
- People urinating and having bowel movements in such a public way can be major sources of embarrassment and frustration. They should not have to wait to use the equipment or to have it taken away when they are done. Anything you can do to help people maintain their sense of control at this time will be an invaluable gift.
- People do not have to have a bowel movement everyday to be healthy. It varies from person to person. They will know if the frequency of their bowel movements is normal or abnormal.

- Menstruating women should have all the supplies and assistance they need. Again ask them what they need and what kind of help would be appreciated and who they prefer to help them.
- If they can help: have them lay on their back, bend their knees so their feet are flat on the mattress and ask them to lift their buttocks while you put the bedpan under them.
- If they prefer, they can roll onto the bedpan: have the person roll onto their side; place the bedpan against their buttocks and ask them to roll onto their back.
- If they cannot lift themselves or roll onto a bedpan, assist them to roll onto their side. They may be able to tell you how to help them. Place an incontinence pad on the mattress (if there is not one already) and put the bedpan on the mattress in the correct spot (often a little dent in the mattress where person was laying) and assist them to roll onto the bedpan. You may need to adjust it a little for comfort.



## **If Someone is Incontinent of Urine or Feces**

Incontinence means that the person cannot control their bladder or bowel movements. Odor problems, infections or rashes may develop if the person does not regularly change and keep dry. Their skin care becomes especially important at this point to prevent painful bedsores and other uncomfortable skin conditions.

- Get some specific advice from a dietician, visiting home nurse, Home Care Case Manager or your family doctor.

- Put a piece of plastic under the bottom sheet of the bed.
- Use incontinence pads or a clean towel under the person in bed. Change as needed. Reusable incontinence pads or towels should be placed in a sealable container until they are washed. Wash the container with a disinfectant and air out regularly to diminish odor. Sometimes having a vinegar and water solution in the container helps minimize odor as well. Non-reusable incontinence pads should be sealed into an airtight garbage bag and kept outdoors and away from the person's room. Oranges with cloves stuck in them, and left in the room, can also reduce odors. There are also commercial products to help with odor. Ask your visiting home nurse or home care case manager about suitable products for your situation.
- Make sure the person's skin remains clean and dry. Use soapy water, and pat as needed.<sup>1</sup> You may also want to use a water-resistant cream to protect the skin. Bedsores are frequently a result of damp skin and poor blood circulation. They are extremely painful and dangerous. Anything you do to keep the skin clean, dry and massaged (to get equal blood flow) will help immeasurably. You will also need to keep bedclothes dry at all times.
- Pajamas bottoms are not very practical. Long T-shirts, pajamas tops or oversized flannel shirts are quite comfortable. Socks may also help keep someone warm in cool temperatures.
- The person may want to use adult diapers to keep dry and comfortable and to allow them to get out of bed and walk around for a bit for

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<sup>1</sup> Editor's Note: After using soapy water, rinse and pat gently as needed

exercise. Check to see if these, and other supplies, are covered by your local Home Care Program.<sup>1</sup>

## **Helping with a Bath or Shower**

When the person can go into the bath or shower you may find the following tips useful:

- Before the person goes into the bathroom, have all the things they will need ready. Run the bath and check the water for the person's preferred temperature. Have the soap, washcloth, shampoo and other items (razor blade, cream, etc) nearby. Have the towels within easy reach. If possible, put the towels in the dryer for two minutes to warm them up so the person can feel warm when they dry themselves.
- Helping people to stand up or sit/lie down can be very difficult on your own body. It is important to remember all the rules of lifting and leaning over that you were taught in school. Remember to bend at the knees when you are picking up an object and keep your back as straight as possible.<sup>2</sup> Remember as well, that the closer you are to the person or object you are lifting, the less strain you put on your lower back, arms and legs. Some regular squatting exercises will help strengthen your legs and lower back.
- If you get quite sore by helping someone get up or down, ask your family doctor, visiting home nurse, occupational therapist or chiropractor to give you clearer instructions of how to lift someone properly so that you do not continue to hurt yourself.

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<sup>1</sup> Editor's Note: These may also be covered through prescription or Non-Insured Health Benefits. Check with FNIHB nurse.

<sup>2</sup> Editor's Note: Do not bend at the waist.

- Help the person into the bath or shower making sure you bend your knees slightly and keep your back as straight as you can. You may want to put a long towel under their arms to help lower them into the bath.
- If the person is able to help themselves more, you can help them sit on the side of the tub (on a warm, non-slip towel or mat), swing their legs over and help them to ease into the tub. Reverse the procedure when they want to get out.
- Make sure the bath or shower has a non-slip bath mat.
- If the person needs help for weeks or months, it may be wise to adapt your bath or shower with handles<sup>1</sup> and other safety aids. Check with an occupational therapist or physiotherapist through your home care program.
- If the person prefers a shower, rent or borrow a bath chair or use a water-resistant chair<sup>2</sup> so they can sit down comfortably. Your home care program may be able to arrange this.
- The person may feel more comfortable if their genital area is covered. You can use a short apron or modified towel with Velcro tabs so the person has the privacy they want.

## **Giving a Bed Bath**

Bed baths may be a little (or a lot) embarrassing for people. However, they are necessary for people who cannot take a bath or shower. The person must stay clean and dry throughout the day and night. Bed baths can be quite comforting because they allow a little exercise, improve blood circulation and also provide an opportunity for gentle massage and a chat if the person would

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<sup>1</sup> Editor's Note: These are called grab bars

<sup>2</sup> Editor's Note: You can also use a (Rubbermaid) 2 step-stool with the steps facing the persons' back.



enjoy that. They also give you a chance to check for bedsores, bruises, rashes and other skin conditions. Bed baths are an intimate experience and must be done with respect and compassion. They should not be rushed. You may even want some music playing in the background for mutual enjoyment.

My father and I were very shy the first time we helped wash my mother in bed. We didn't know what we were doing so my father and I washed her from top to bottom, all at once. Then we dried her from top to bottom, all at once. She froze. We learned *wash and dry one part at a time and keep the rest covered for warmth!*

**What you will need:**

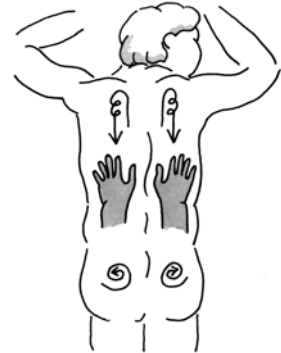
- A large bowl or basin filled with hot water (hot enough to be warming)
- Mild soap
- Skin lotion, cream and/or powder
- Washcloths (for washing and rinsing) and towels
- Personal toiletries: comb, brush, tooth brush and paste, nail file and clippers, make-up, deodorant, shaving items, perfume/cologne (whatever the person needs)
- A suitable change of clothes.

**What you do:**

- Wash your hands thoroughly and try and make the room temperature comfortably warm/cool, depending on the season.
- Let the person do as much as possible for themselves. If they cannot do much themselves:

- Wash one body part at a time starting at the face and working down or in the reverse direction; whichever the person prefers. The rest of the body should be covered with the top bed sheet, flannelette, or a large towel.
- During a bed bath, you may also put a basin of water on a towel at the foot of the bed, and help the person soak one foot at a time in the basin. It is very comforting. Towel dry the feet when they are finished, including between the toes.
- Wash carefully under the skin folds since these are the most likely spots for rashes or other skin problems. This is especially true under the arm, in the groin area, buttocks, stomach skin folds, and under a woman's breasts. In sensitive areas, the person may be able to help with the washing more than in other areas
- Cleaning the back is the perfect opportunity to give someone a back rub whether they are on their stomach or on their side. Once you have cleaned them you can use skin lotion to evenly massage the upper and lower back and buttocks. Ask the person how they like their backs rubbed best and follow their lead. Use soft or harder pressure depending on what they prefer and move your hands in circular motions. Do it several times, always keeping your hands on the person's skin and using enough lotion so that your hands move smoothly.
- People often enjoy having their face, temples, neck, hands, elbows, feet and heels massaged as well. Again follow their wishes.

- Once you have completely washed and dried the person, help them with their personal hygiene. For example, they may want to use deodorant, put on some makeup, have their hair combed, etc.
- Help them put on their clothes in whatever way they ask.



## General Hair Care

People need their hair clean, combed/brushed (at least twice a day), cut and set. The condition of one's hair often tells visitors and the person themselves how well they are doing. Clean and groomed hair is important for good health and feeling good about yourself.

## Dry Shampoo

You can wash someone's hair using 'dry' shampoo like a commercial dry shampoo, cornstarch or natural (unscented) talcum powder. This method was all the rage in the late 1960s and early 1970s for teenagers -- I remember it well!

For someone who needs their hair washed in bed, dry shampoo can sometimes be a quick alternative to a normal wash. Do the following:

1. Place a towel under the person's head.
2. Sprinkle powder on the scalp and massage the hair and scalp gently.

3. Brush the powder out of the hair with slow, even strokes. If hair is tangled, hold it firmly near the scalp before brushing through to the end.
4. Wash the hairbrush after each dry shampooing.

## **Wet Shampoo**

If the person needs a normal hair wash but cannot use the bath or shower, you can wash their hair in bed. You will need:

- A plastic sheet to protect the bed
- A waterproof cape (like in a hair salon) or a plastic garbage bag with a hole for the head and cut along the sides to make a cape
- A jug or pitcher of warm-to-hot water (several if the person has long hair)
- A bucket or large basin to collect water, (there are also special shampoo trays available through some drug stores)
- A wash cloth or small towel, plus two larger towels for drying
- Pillow(s)
- Shampoo
- Comb or brush
- A hair dryer (if needed)



**To help the person wash their hair if they are not able to do it themselves:**

- You may want to put a towel or plastic sheet on the floor under the bucket to catch any spilled water.
- Have the person lie on their back with their head over the side of the bed (adjust pillows, covers, etc. so they are comfortable). Put the bucket or basin on a small table under the person's hair.
- Cover the area with the plastic sheet and have the person wear their cape with the back side covering their pillow rather than tucked under them.
- Pour warm water from the jug over their hair so that the water falls in the bucket or basin below.
- Put the shampoo into the hair and gently massage it in to lather the hair and scalp.
- Rinse the hair with the remaining water.
- Dry the hair with a towel and then with the dryer if necessary.
- Empty the bucket and remove the cape and plastic sheet. Place the other dry towel on the pillow to soak up any moisture still in the hair.<sup>1</sup>
- Other tasks like setting or coloring the hair can be done in bed using the same common sense approach to comfort and cleaning as described here.

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<sup>1</sup> Editor's Note: Remember to tidy up the bed.

## **Taking Care of Someone's Back**

Many people like a back rub whether they get a bed bath or not. If the person agrees, you can give them a back rub while they lie on their stomach or on their side just as in the diagram earlier. Use a good skin lotion or experiment with natural oils such as rose or almond oil. Check with the visiting home nurse or family doctor for suggestions.

If the person cannot turn in bed themselves, they will need to be turned every two hours or so. Otherwise there will be too much pressure on just one part of their skin and they risk getting bedsores. Each time they are moved you may want to gently rub the skin where they have been laying to improve the general circulation of blood into that area. You may also want to give it a quick wash if the person has been sweating a lot. Use pillows to provide the back support they need when they are on their sides. There are some diagrams in this book that show proper pillow supports in different lying positions.

## **Other Areas Needing Care**

Most people can brush their own teeth (or soak dentures), clean their mouths, ears and nose. Some people may need a little bit of assistance. Let them direct you how you can best help. They may need extra help especially with their fingernails. You might brighten up a loved one's day by helping her to use her favorite nail polish.

Feet and toenails may require a good footbath (with person sitting in chair or lying in bed with basin on a towel on the mattress). It is important to clean and dry between the toes as well as the rest of the foot. Cream or lotion will help with dryness. A good time to check and trim toenails is after a relaxing foot soak. They should be trimmed in the same shape as their toes without sharp edges to prevent damage to other toes. The person may also enjoy a foot massage.

## **Adaptive Clothing**

If someone must stay in bed for a long time or if they must stay around the home for long periods they may wish to adapt some of their clothes to make care easier on themselves and for others.

For example, rather than long pants or pajamas bottoms, they may wear oversized shirts or pajamas tops that are buttoned in front to keep their upper and lower body warm while also making it easier to get dressed and undressed. Sometimes, the back part of a shirt or pajamas top can get wrinkled and be quite uncomfortable for someone lying in bed for a long time. It may be worth taking some older shirts/pajamas tops and cutting up the back and sewing a seam on each side (much like those wonderful hospital gowns everyone loves to wear). Use a strip of extra cloth to make a tie at the top and middle if you like. You can also use oversize shirts/pajamas tops and

put them on backwards for a similar effect although they may not fit as nicely and may need a little cutting and sewing to fit better around the neck.

Scarves (light or heavy) may be very useful to make sure that someone remains warm if there is a draft. Also scarves can be used to keep one's head warm if the person has lost their hair during treatments. The book *Changes, Choices and Challenges* (in the reference section) gives examples of the creative uses of scarves and cosmetics. Socks or good slippers will also help keep feet warm.



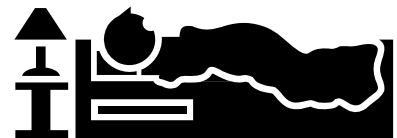
# BED CARE

## Supported Lying Positions

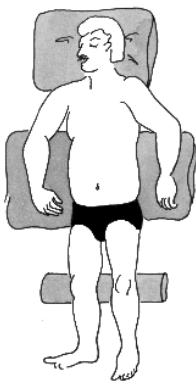
People need to rest in different lying positions so that they do not put too much pressure on any single body part or skin area. People can sit up, lay down or lay on their sides as they normally do for a sleep.

### Sitting Up

The head should be raised about 45°-60° with small pillows under their head, lower back and under their knees (or raise the foot portion of the bed). This position is helpful for eating, using a bedpan or urinal and helps improve the person's heart and lung work. If the person likes a large pillow, place it lengthwise to support their upper back, shoulders and head. It may help to have a footboard<sup>1</sup> at the bottom of their feet to allow them to push up a little as they will naturally slide down in bed over time.



### Lying Down



With the person in the center of the bed, put a pillow under their shoulders, neck and head. Another pillow can go under their lower back for extra support and a rolled up towel or smaller pillow under their ankles and knees. The person may also enjoy pillows under the upper arms and hands. Follow the person's wishes and change pillow positions as requested.

<sup>1</sup> Editor's Note: Footboard should be padded – foam, blankets or towels can be used for padding.

## **Lying on the Side**

When you look at a person lying on their side, you should see the same body position as if they were standing with their top leg bent up. The back is in line with the straight leg, with pillows under the head, top arm and bent leg. Pillows are also often rolled along their back for extra support.



## **Making a Bed**

People may spend a lot of time in bed. It is important that the bed stay clean, dry and comfortable.

## **Making an Unoccupied Bed**

It seems silly to have a section on making a bed. Add to that that my mother would be amazed that I am offering advice on this subject and you get the idea that you should accept or reject any of the following advice based on your own expertise. However, many of us have never had to make a bed for

someone who will spend days there. How you make the bed will decide how comfortable the person may be.

Try to use fitted bottom sheets so that the sheet has few wrinkles in it. Wrinkles add extra pressure to the person's skin and may cause bedsores. If you can, try to make the bed when the person is normally not in it (e.g. when they are taking a bath or sitting in a chair reading the morning paper). Try to avoid extra efforts to get the person out of bed just so that you can change it. The more natural the effort, the less trouble for everyone.

## **Making an Occupied Bed**

Sometimes the person in bed cannot get out for you to change the sheets. This takes a little more planning but is quite simple after a few tries. The idea is to make one side of the bed at a time. Follow these steps:

1. Make sure you have all the clean sheets, pillowcases, etc. that you need on a chair beside the bed.
2. If possible, have the bed lying flat (if it adjustable) and the person using only one pillow.
3. Place a chair on the opposite side of the bed you are working on. If you are using a hospital bed you can raise the far side up. Either way will allow the person in bed to hold onto something as they roll onto their side close to the chair or bed rail, their back toward you. They should be covered with a top sheet, blanket or cover so they can stay warm.
4. Loosen the bottom sheet at the head and feet end of the bed, as well as any top sheets and blankets. Roll the bottom sheet as closely to the

back of the person's body as possible. They will have to roll over this old sheet and onto the new one when you are ready.

5. Smooth out the mattress cover.
6. Place the clean fitted bottom sheet, folded lengthwise, from head to foot ends of the bed. Tuck in the head and foot ends and smooth out the sheet as much as possible.
7. Roll the remaining bottom sheet, lengthwise, as closely to the back of the person's body as possible. It will be right beside the old bottom sheet.



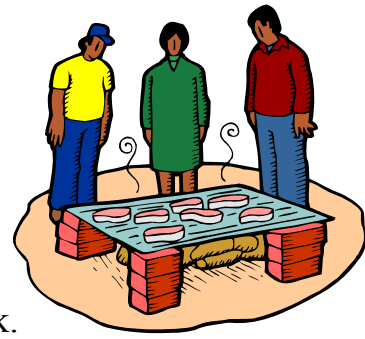
8. Ask (or help) the person to roll toward you, over the sheets. If they need extra support, have them roll onto their back first, lift their far leg towards you gently, and help them roll onto their side facing you. Bring the chair from the other side to put where you were standing so that the person has something to hold onto and help prevent them from falling out of bed.
9. Move to the other side of the bed. Loosen the old bottom sheet and pull it completely off the bed as well as pulling the new sheet from under the person. Some of the sheets might be caught a little under the body weight of the person in bed, but just pull gently until they are loose. If necessary, gently push the bottom part of the person's back to release some of the body weight on the sheets. Smooth the mattress cover.
10. Tuck in the new bottom sheet at the head and foot end of the bed and make sure there are few, if any, wrinkles.

11. Have the person lie on their back and position the bed comfortably for them. Replace old pillowcases.
12. If the person uses a duvet, replace the outside cover as needed.
13. If the person uses sheets and blankets they will already be untucked from replacing the bottom sheets. Place a clean sheet on top of the blanket. If possible, put the new sheet in a dryer for a few minutes so it is toasty warm. Have the person hold onto the blanket and clean sheet as you pull out the old top sheet from the foot of the bed. Flip the new sheet and blanket over into the right place. If they cannot help you, you will have to do this yourself and it may take a little more time.
14. Turn the sheet and blanket around so that the blanket is on top and tuck in the top sheet and blankets (and bed spread if they like).

### Extra Tips

Sometimes there may be other things on the bottom sheet that will need to be changed or at least kept there. For example, draw sheets, sheepskin pads and incontinence pads are often used for someone who is in bed. (If possible, put the sheep's skin in the dryer on 'air' for a few minutes to fluff up the wool.) In changing the bed, the same principles apply as in the instructions above. You do one side of the bed at a time and the person needs to roll over the old and new items you are changing. The more things there are, the higher the 'bump' the person has to roll over.

# Not Feeling Hunger Not Eating Very Much



This is a normal response for people who are very sick.

They may feel less hungry and thirsty because they are not as active and their bodies become unable to process food as they normally would.

It is understandably hard to watch those you and the family care for eat less than usual. However, it is wise to offer small portions of favourite foods or fluids and encourage them to eat and drink only as much as they want.

You May Notice the Person:

- Eats very little, is not interested in food or may feel unable to eat.
- Refuses solids and will only drink liquids.
- Loses weight.

Comfort Measures:

- Be positive.
- Don't make an issue of how much or how little he/she is eating.
- Give nourishing snacks, soups, eggnogs or ice cream.
- Serve small portions of favorite foods that are soft and easy to eat.
- You cannot force the person to eat.
- Make mealtime a social occasion.
- Freshen and clean the person's mouth before and after eating.
- If dentures are loose, have them relined or try Poly grip.

- Each person will have different tolerance level for fruits and vegetables. Prunes and other raw fruits and vegetables can relieve constipation. Vegetables cooked in soups are soft and well tolerated.

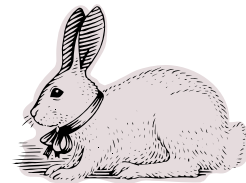
- Breads and cereals are often well tolerated. Bran and whole grain cereals/breads are particularly helpful in preventing constipation. Crackers and plain cookies can be good in alleviating nausea.



- Eating protein in any form should be encouraged. Milk and milk products, such as macaroni and cheese, cottage cheese, yogurt, baked custard, ice cream, eggnog and milkshakes are good sources of protein. Many indigenous people are lactose intolerant as they age. If the person has diarrhoea from lactose intolerance, a good nutritional supplement may be necessary. Meat, poultry, eggs and fish are also very high in protein. They can be stewed, creamed or poached to soften them into a more easily digested form.
- Fluid intake should be encouraged. Clear soups, ginger ale, soda and fruit nectars are recommended. Tea can also be served. Citrus juices may be difficult to digest or aggravate mouth ulcers.
- If feeling nausea/feeling sick to the stomach is a problem, tell your health care worker, elder or doctor. Anti-nausea medications can be very helpful.

### Traditional Soothing Remedies:

- Chamomile tea
- Rabbit skins – tie to feet and hands
- Rub tips of toes and fingers (reflexology)



# Difficulty Swallowing

Serve:

- Moist food
- Pureed or minced food
- Baby food
- Nutritional supplements



# Strong Dislike for Certain Tastes

Serve:

- Other food sources

Examples: If the person has a dislike for sweet foods, serve unsweetened food

If the person doesn't care for red meats, serve other high protein foods like eggs, poultry or fish

- Avoid very seasoned or salty food.



# Feeling Sick and Throwing Up

Several things can cause common problems, in a progressive disease. (i.e. irritation or pressure on the digestive system) It can also be an early side effect of the pain medication. The cause can be discussed with a health care provider.

## You May Notice:

- The person feels sick and is unable to eat
- They may vomit occasionally or often
- They may have trouble keeping down medication
- They are comfortable at rest but feel sick with movement
- They may be sensitive to strong smells/tastes (i.e. cigarettes or cooking smells)

## Serve:

- Small meals
- Crackers first thing in the morning
- Starchy foods (rice, pasta, potato)
- Clear fluids (broth, jello, ginger ale)
- Cold foods that do not stimulate sense of smell (salads, sandwiches)

## Avoid Serving:

- Liquids with solid food
- Overly greasy, sweet or spicy food

## Comfort Measures:

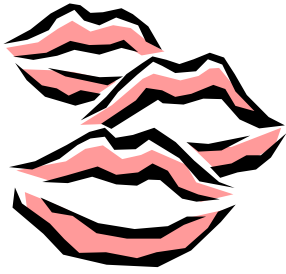
- Encourage them to adjust their diet, i.e., small amounts of clear fluids
- Encourage them to take the anti-nausea medication regularly
- Ask about other ways for the medication to be given. (i.e. a suppository patch)
- Freshen the mouth with mouthwash or toothpaste



- Traditional methods suggest scraping Red Willow bark to drink to cause vomiting which cleanses the inside.
- The basin with vomit in it should be cleaned and removed immediately
- Fresh air may help



# Mouth Care



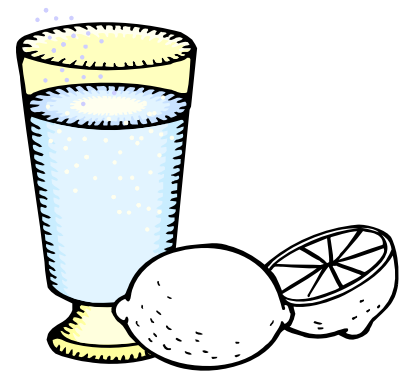
Sore mouths are often common. People are unable to drink their usual amounts of fluids. This may happen with nausea, vomiting and/or lack of appetite. When body fluids are reduced, saliva may dry up. If the person breathes through their mouth, it can be worsened.

## You May Notice:

- The person's mouth feels dry and uncomfortable.
- The tongue may be red and coated.
- The lips may be dry and cracked.
- There may be a bad taste in the mouth.

## Comfort Measures:

- Clean the mouth frequently.
- Check commercial mouth washes. Some have alcohol and may make the dryness worse.
- Rinsing with other solutions may be helpful.
- After cleaning the mouth, lubricate lips.
- Small amounts of fluids taken as often as possible are best. Sips of water or diluted juices are best if nausea and vomiting are a problem.
- Sucking on ice chips or popsicles can help.
- Add a small amount of lemon juice to water and crushed ice to stimulate saliva.



### For the Person Who Can No Longer Manage to Do Mouth Care:

- Remove and brush dentures once daily. Swab the mouth with a swab stick or gauze moistened in mouthwash (water, baking soda) after the dentures are removed.
- Mos-istir sticks may help. These are purchased in a drug store.
- After cleaning the mouth, lubricate lips. Vaseline is good unless the person has oxygen.

### Sore Mouth:

#### Serve:

- Soft, bland foods
- Cold foods and liquids
- Cold nutritional supplements
- Popsicles, ice cream



#### Avoid:

- Foods, which are spicy, hot, acidic.

### Four Other Recipe Suggestions:

4 cups water, 1 teaspoon salt, 1 teaspoon baking soda

1 oz. Ginger Ale and 2 teaspoons baking soda

Natural methods (i.e., cedar water)

# Recipes for Mouthwash

**1**



4 cups of water

1 teaspoon of  
baking soda

1 teaspoon of  
salt

**2**



1 oz.

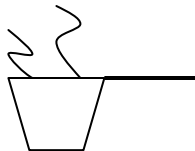


1 oz.  
Ginger Ale



2 teaspoons  
baking soda

**3**



Cedar greenery

Boiling water

## THRUSH INFECTION

Thrush in the mouth sometimes occurs due to a lowered body resistance to infection.

### You May Notice:

- Patches of white curds on the tongue or on the inside of the cheeks
- Complaints of a sore throat or burning in the chest.
- Difficulty swallowing.
- A swollen, reddened tongue.

### Comfort Measures:

- Medication obtained from a health care provider, i.e. Mycostatin
- Clean the mouth by rinsing with mouth wash or plain water after eating
- White patches can be gently removed with a soft toothbrush when they become loose
- Soak dentures overnight in full strength Listerine, rinsing before they are put back in the mouth.
- Cedar and water
- Slippery elm (can be bought in stores)
- Sweet Flay - wega
- Sage – as on sores

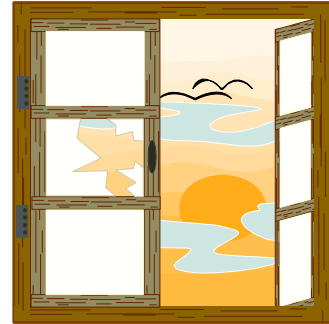


# Difficulty in Breathing

This may be due to physical changes due to progression of the disease. The person can discuss it with their health care provider.

## You May Notice:

- May become breathless with movement, dressing
- Breathless at rest
- May sound congested
- May cough up mucus or feel the need to cough up mucus but is unable to
- May feel frightened



## Comfort Measures:

- Plan for rest periods between activities.
- If talking makes the person feel breathless, limit visits if that is what the person wants.
- Medications may help.
- Humidity may help to cough up the mucous.
- Fresh air (opening the window) or turning on a fan.
- Remove tight clothing that makes the person feel tight or constricted.
- Change positions; usually sitting straight up is best.
- A recliner for rest may help the person sit semi-upright.
- If anxious have someone talk to them.
- Relaxation exercises, music, tensing of the muscles will add to the feeling of breathlessness.
- Talk to the person before air fresheners or household cleaning products are used.

*Speak to health care provider if breathlessness is troublesome.*

# Skin Problems

Sore areas or breaks in the skin can occur if the person has lost weight and has to be in bed for long periods of time.

Prevention is the best cure.

You May Notice the Person:

- Develops red, sore skin at pressure areas such as the tailbone, elbows and heels.
- Has broken areas in the skin, itchy areas or rashes.



Comfort Measures:

- Change the person's position every 2 to 4 hours. Show the family/helper how to move the person safely and protect themselves as well.
- Use small pillows (such as rolled up towels) to put between knees and to protect other areas from contact with bedding.
- Keep skin folds and creases clean by daily sponge baths. Dry thoroughly. Daily baths may not be necessary if very drying to the skin.
- Use bath oils and lotions to help dry or itchy skin. If cream is applied, use sparingly and rub in gently to avoid the irritation of wet creams.
- Put extra padding on the bed to cushion the person: egg crate foam, sheepskin pads, special mattresses. Talk to your health care provider about the choices that are available.
- Talk to your health care provider about any reddened or open areas in the skin. There are protective dressings that can be applied to sensitive skin or open areas that will reduce irritation and provide comfort.



## Traditional Comfort Measures:

- Bear grease can be applied to skin
- Milkweed (sesab)
- White Spruce – used for skin eczema (no need to boil)
- Singe the rabbit skin and rub on skin to get rid of itchiness

Alder tree– atobin

Ash tree – mitigomish

Chokecherry tree – asaweminagosh

Saskatoon tree– osigwagaminagosh

Pin Cherry tree– bawaominanagosh

Thorn bush tree– minesagosh



Always offer tobacco before picking and when the picking starts, go from the EAST and pick clockwise.

Use the bark of the trees – ash, choke cherry, Saskatoon, pin cherry, thorn bush and alder. Boil about a gallon and wash self. The lotion turns into a jelly.

When the person is receiving care, observe to find out if they are in pain. They may need more medication or choose to pass up their bath for the day until the increased dose of medication takes effect. There are medications that can be given just before turning or changing dressings.

In the last few hours of life, the person may not want to be disturbed.



# Feeling Weak

This usually happens over weeks and months, but it can also happen fairly quickly over a matter of days. As the person gets weaker, you will need to change the way you do things. For example, using equipment such as a walker or wheelchair can provide safety and make care in the home easier.

You May Notice The Person:

- Tires more easily and needs to nap often.
- Becomes tired or exhausted after activities that once were easy.
- Becomes short of breath with moving or talking.
- Needs help to walk, bathe or dress.
- Feels anxious or frustrated with changes in energy and strength.
- Becomes extremely weak and may need to be cared for in bed.



Comfort Measures:

- Show the family and the person ways to help the person move more easily. A Nurse/Community Health Representative/Occupational Therapist may have suggestions.
- Give reassurance. Loss of independence can be upsetting for the person.
- Find a way the person can call for help if needed, i.e., bell to jingle or a plastic cup to bang on
- Talk about ways to rest beforehand so they can do the things they want to do.

# Constipation

This is a common problem that can be caused by the progress of the disease, changes in diet and decreased activity. If taking narcotics for pain control, this will slow the movement of the bowel.

It is important that pain medications be taken. Medications to counteract the effect of the slowing of the bowel by the opioids can and will be given.

## You May Notice:

- Bowel movements will be less regular and sometimes not for days at a time.
- The stool is hard and straining is needed to have a bowel movement.

## Comfort Measures:

- Taking bowel medications as advised by the health care provider is important
- If nausea is not a problem, fruit juices, fluids of all kinds and natural laxatives such as prunes may be helpful.
- If there is no bowel movement in three days, it is important to tell your health care provider so they can adjust the medication, order a suppository or an enema.

## Natural Remedies:

- Labrador tea – can be picked and boiled
- Prunes
- Take plenty of orange/apple juice
- Bran cereals



- Whole grains
- Fibre Spread Recipe: 1 cup All Bran; 1 cup apple sauce; ½ cup prune juice. Mix together allowing All Bran to soften. Use 1 – 2 tsp./ day on crackers, toast or mixed in cereal. Increase fluid intake.

# Not Sleeping Well and Feeling Tired

## What is Feeling Tired?

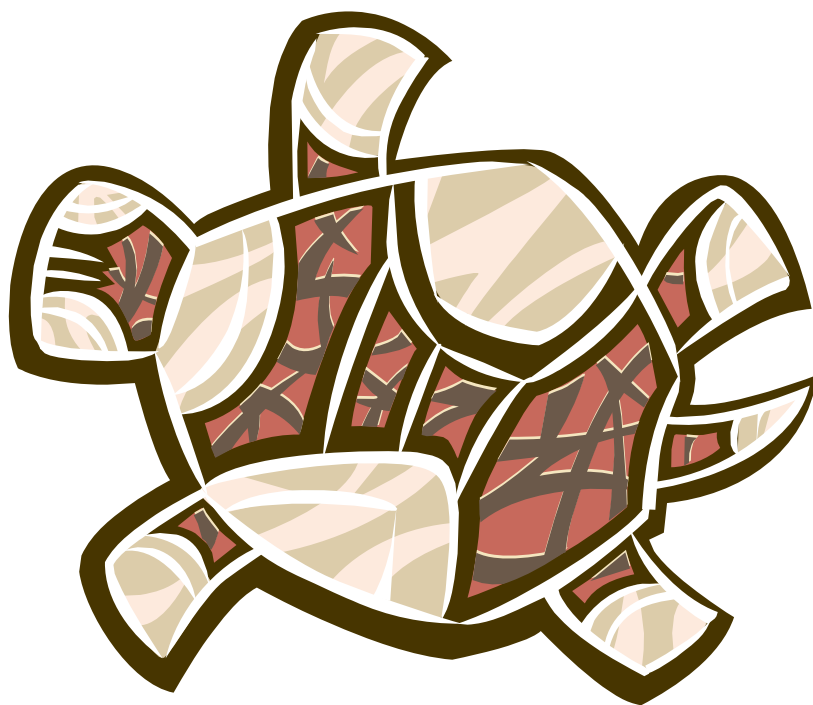
Feeling tired can leave you weak or run down. However, there are other signs of “Feeling Tired”:

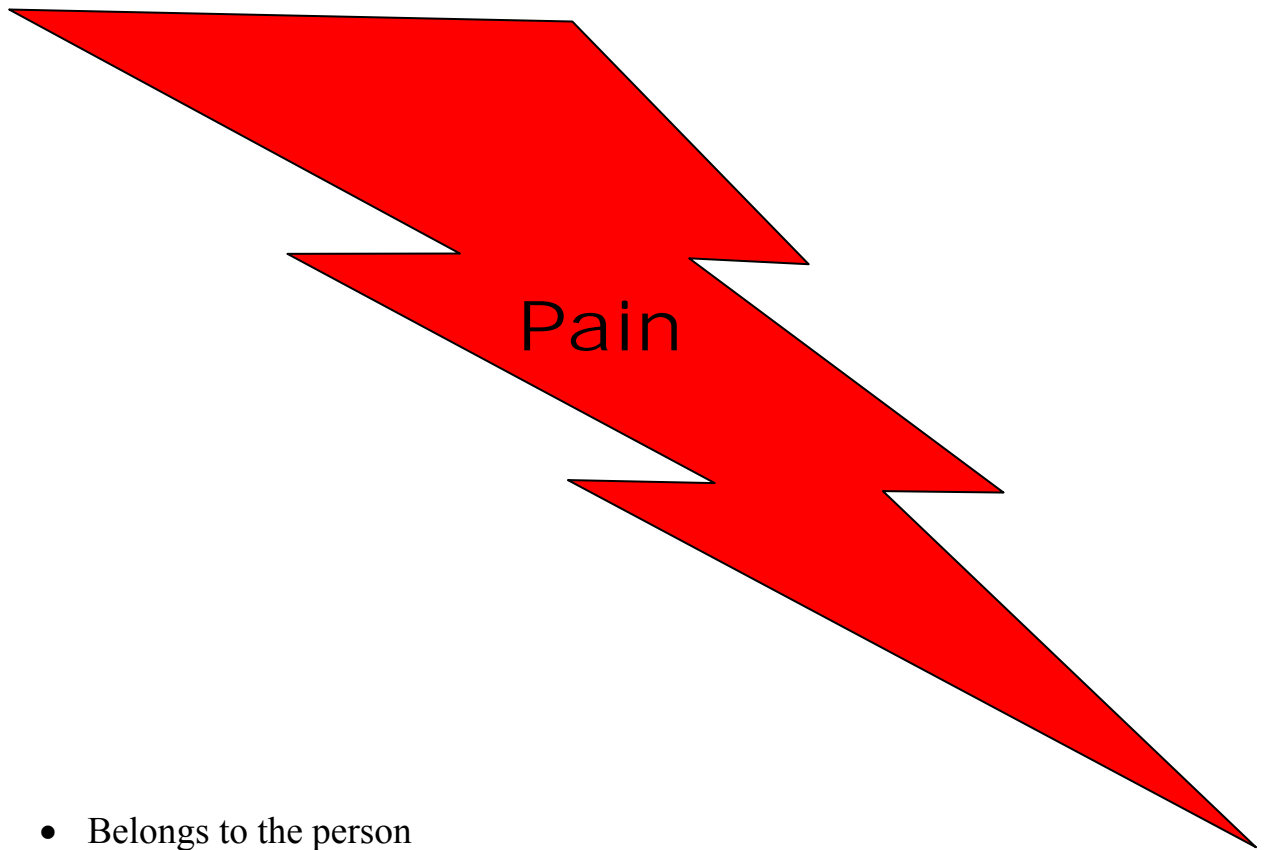
- Pain in your legs
- Having problems climbing stairs or walking short distances
- Being short of breath after a light activity
- It can also affect the way you think and feel
- It can make you lose interest in your pastimes
- It can make you impatient



## Things That Can Help

- Take several short naps or breaks, rather than one, long rest period
- Plan your day so that you have time to rest
- Take short walks or do some light exercise if possible
- Try easier or short versions of the activities you enjoy
- Eat as well as you can and drink plenty of fluids
- Ask family or friends to help with tasks you find difficult
- Do things that are less difficult, like listening to music or reading
- Keep a diary of how you feel each day – this will help you with planning your daily activities and can help you and your doctor determine if you need medicines to help with being tired





- Belongs to the person
- Is enough to make them uncomfortable.
- Is what the person says it is and not what others think it should be.
- It occurs where the person says it occurs, and it as bad as the person says it is.

## THE SIGNS OF PAIN

Some people may feel pain but deny it. It is important to look for signs of pain:

- General body tension: clenched hands, hunched shoulders
- Tense facial expressions
- Constant fidgeting
- Nervous habits: lip and nail biting
- Unexplained withdrawal
- Strained or high-pitched tone of voice



## PAIN:

- May be constant and unlikely to go away, or come and go.
- Usually due to the disease but may be due to arthritis or muscle stiffness because they don't move as much as they used to.
- Can affect moods and can be affected by thoughts or emotions.
- Is usually treated with medication on a regular basis. A smaller dose of medication is usually given to help pain that comes between doses.
- Usually medications like Tylenol are used for mild pain and the stronger medication such as codeine and morphine are used as the pain becomes worse

**“A constant source of discomfort requires a constant source of relief”**

**It is possible for most people to be comfortable and alert until they die.**



## Finding out about the pain

Some questions you might ask:

- Tell me about your pain
- When do you get the pain? Walking? At rest?
- Where is the pain? Does it spread?
- How bad is it? (mild or severe)
- What makes it worse?
- What makes it better?
- Does it affect your sleep? Activity? Mood? Visiting with family?
- What medications, therapies or natural ways have you tried?
- Report any change in the pain to the health provider.

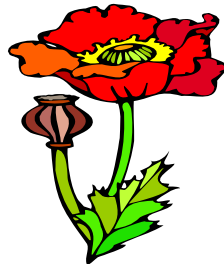
Listen

Listen

Listen



# What May Help



## Medications:

Many people have strong thoughts and feelings about pain medications.

Some people feel:

- “Taking pills isn’t natural”  
For a person with a serious disease medication may make the difference between being in pain and doing the things they want to do.
- “They will get addicted”  
For a person with severe pain, the pain takes care of the medication. If the person has radiation or some special treatment that makes the pain go away, the medication can be reduced gradually and stopped.
- “They will feel high”  
Only if they take the medicine for reasons other than pain.
- “The medication will not work later on when the pain is very bad”  
Now we know you can gradually increase the dose until there is pain relief. We now know we can use much higher doses.
- “They will be sleepy”  
This may happen at first, especially if the person hasn’t slept for a few days. They will adjust. If sleepiness continues, their health care provider may add other medications.

## Taking Medication:

- Medications should be taken regularly including during the night. The medicines may be ordered every 4 hours for a short acting medication or every 12 hours for a long acting medicine. There is usually a “break

through or rescue dose” that the person can take in between if the pain is bad. If the person needs several rescue doses, they may need to have their regular dose increased. Talk to the health care provider.

- Each person responds to medication differently so pain medication is ordered individually. The weaker medication will be ordered for mild pain in the early stages.
- As the pain worsens, a stronger medication such as a narcotic/opioid may be ordered. Other medicine may be added, for example, Tylenol with codeine. Strong pain is usually given strong medication.
- Keeping track of when and how often the medications are taken is easier to do if a medication record is used.
- Preparing the medications ahead of time helps. An egg carton or dosette can work for separating out the pills throughout the day.

“A constant source of discomfort requires a constant source of relief”

### Swallowing Pills:

- Swallowing water first and placing the pills at the back of the tongue and then swallowing more water may help. Some pills can be mixed in applesauce or pudding. It is important to talk to the health care provider before crushing pills as some cannot be crushed, i.e., MS-Contin (long lasting morphine)
- Medication may come in other forms such as liquids, suppositories or injections given under the skin. The person may be changed to a patch.



## **Medication Side Effects:**

Observe for side effects of the opioids (i.e. codeine, morphine) and discuss with health care provider.

Many medications are available to help with these side effects.

## **Common Side Effects**

- Constipation (laxative must be ordered)
- Dry mouth
- Nausea & vomiting
- Drowsiness for a short time

## **Less Common Side Effects**

- Hallucinations (when a large amount of opioid is ordered)
- Very slow breathing
- Jerking
- Difficulty voiding - usually elderly only
- Confusion

Hallucinations, confusion and jerking may be a sign that the medication needs changing. A health care provider can help with this

## Other Ways to Help With the Pain:

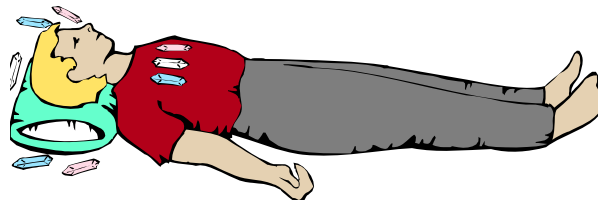
- Distraction
  - ✓ Television
  - ✓ Games
  - ✓ Hobbies
  - ✓ Good conversation
- Relaxation
  - ✓ Rhythmic breathing
  - ✓ Isometric exercises
- Imagery
  - ✓ Visualizations
  - ✓ Meditation
- Touch
  - ✓ Stimulate the skin with gentle massage using steady, slow, circular motions
  - ✓ Warm baths or blankets, cold packs
  - ✓ Therapeutic touch
- Pets
- Music



# Isometric Exercise



1. Close your eyes. Breathe slowly and relax.
2. Continue breathing naturally while you tense your toes, hold for ten seconds and then release.
3. Next, tense your feet, hold for ten seconds, then release.
4. Next, tense the calf muscles, hold for ten, and then release.
5. Continue this from toe to head and head to toe:
  - ✓ calf muscles
  - ✓ thigh muscles
  - ✓ buttocks
  - ✓ stomach
  - ✓ arms
  - ✓ shoulders
  - ✓ fingers
  - ✓ neck
  - ✓ face

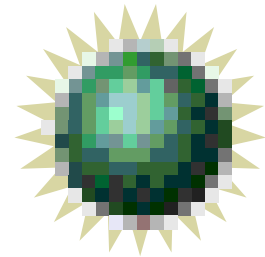


6. After the process is complete, ask the person to determine if any part of their body remains tense and if so, concentrate on relaxing that part by tensing once more.

# Imagery Exercise

## The Ball of Healing Energy

1. Close your eyes. Breathe slowly and feel yourself relax.
2. Concentrate on your breathing. Breathe slowly and comfortably from your abdomen. As you breathe in, say silently and slowly to yourself “In one, two” and “Out one, two.” Breathe in this slow rhythm for a few minutes.
3. Imagine a ball of healing energy, perhaps a white light, forming somewhere in your body. Imagine it taking shape.
4. When you are ready, imagine that the air you breathe in blows this healing ball of energy to any part of your body where you feel pain and discomfort.
5. Continue to breathe naturally and when you breathe out, picture the air moving the ball away from the body, taking with it the pain or discomfort and tension.
6. Continue to picture the ball moving toward you and away each time you breathe in and out.
7. Imagine the ball gets bigger and bigger as it takes more and more discomfort and tension away.
8. When you are ready to end the imagery, count slowly to three, breathe in deeply and open your eyes.



From: The Canadian Cancer Society "Radiation Therapy and You"

# Rhythmic Breathing Exercise

1. Stare at an object, or close your eyes and concentrate on your breathing or on a peaceful scene.
2. Take a slow, deep breath and, as you breathe in, tense your muscles (such as your arms).
3. As you breathe out, relax and feel the tension draining.
4. Now, remain relaxed and begin breathing slowly and comfortably, concentrating on your breathing, taking about six to nine breaths a minute. Do not breathe too deeply.
5. To maintain a slow, even rhythm as you breathe out, you can say silently to yourself, "In one, two and Out one, two." It may be helpful at first if someone counts out loud for you. If you ever feel out of breath, take a deep breath and then continue the slow breathing exercise. Each time you breathe out, feel yourself relaxing and going limp. If some muscles are not relaxed, such as your shoulders, tense them as you breathe in and relax them as you breathe out. You should only need to do this once for each specific muscle.
6. Continue slow rhythmic breathing for a few seconds up to 10 minutes depending on your need.
7. To end your slow rhythmic breathing, count silently and slowly from one to three. Breathe in deeply at the count of three. Open your eyes. Say silently to yourself: "I feel alert and relaxed." Begin moving slowly.

From: The Canadian Cancer Society "Radiation Therapy and You"





# **CARE FOR THE SOCIAL AND EMOTIONAL ASPECT OF THE PERSON**

**When a person and their family find out that an illness is terminal, they may have the following reactions:**



First reactions to the news of a terminal illness:

- Shock
- Denial
- Fear
- Anger
- They may blame others for the illness
- They are probably disorganized



Later Reactions:

- They start to adjust to the illness.
- They start talking about their feelings.
- They become organized to give the needed care.
- They start feeling tired, drained and may become impatient with the dying person.
- They need “time out” and start sharing the responsibilities.



Reactions near the end:

- They accept the reality of death.
- They may feel useless because their care is not making the dying person feel better.
- They may feel frustrated because the medicine is not working.
- They feel sadness and anxiety.
- Some people become very angry or hide their feelings.



## As Time Passes

The person with a terminal illness and their families may have many emotional reactions to the illness and have special emotional needs. They experience many feelings and have special emotional needs.

### Feelings of a Terminally Ill Person

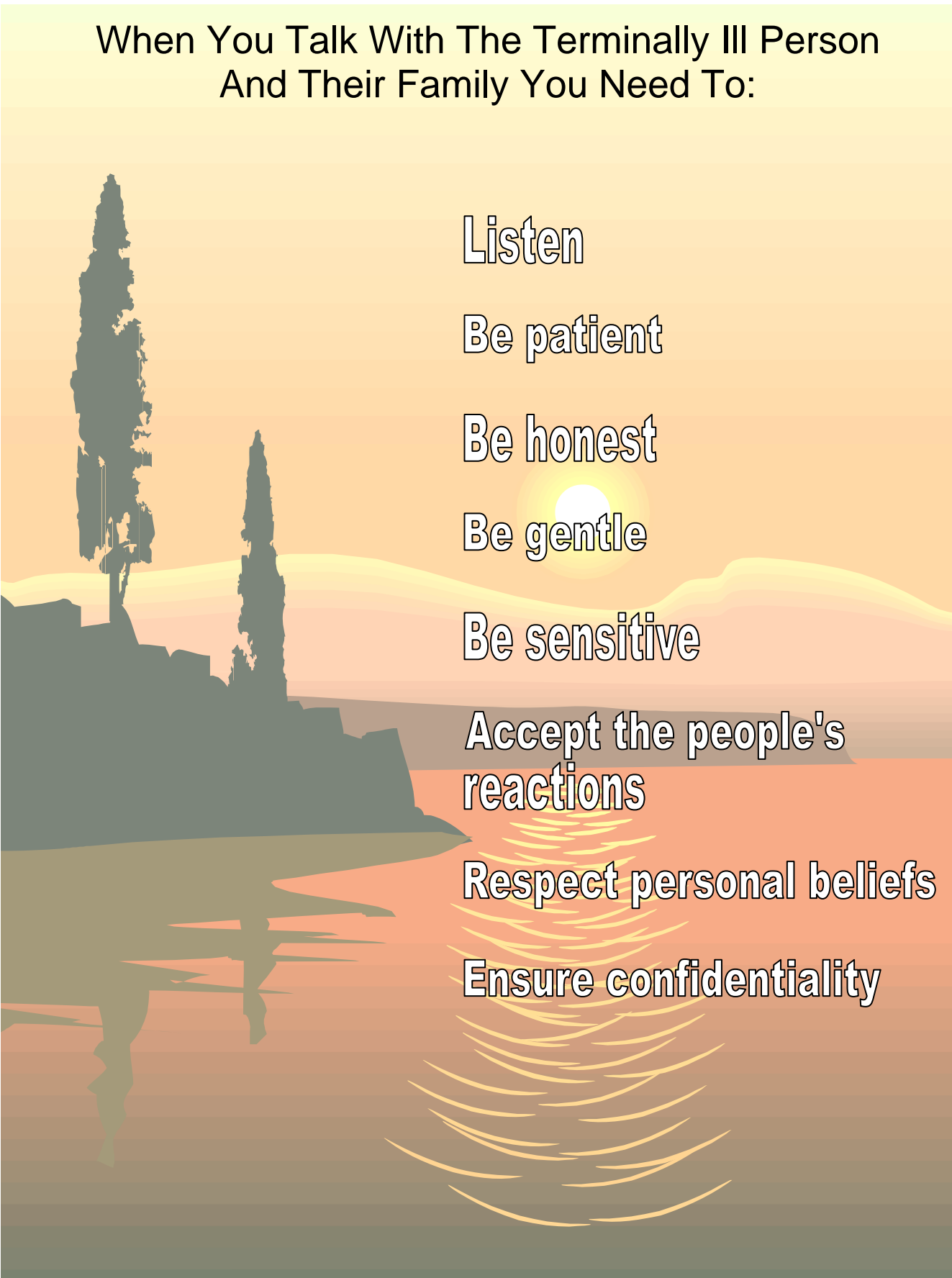
- Lonely
- Afraid
- In Pain
- Confused
- Sad
- Anger
- At Peace



### Emotional Needs of the Dying Person

- Needs companionship
- Needs spiritual comfort
- Needs opportunity to talk to loved ones and express his/her feelings
- Needs loved ones to listen to his/her last words of love and wisdom and special requests
- Needs to appoint someone that will make sure that her/his last wishes are carried out

May need someone to help him/her give away his/her personal things



## When You Talk With The Terminally Ill Person And Their Family You Need To:

Listen

Be patient

Be honest

Be gentle

Be sensitive

Accept the people's  
reactions

Respect personal beliefs

Ensure confidentiality

## CHANGING LEVELS OF AWARENESS WHEN DEATH IS NEAR

As the person's condition worsens, death is becoming closer there will be some changes.

- The person's ability to think and respond clearly can be affected
- Sometimes people seem to be confused or to hallucinate. They experience a reality different from ours, often seeing or hearing people who are not physically present and usually feel quite comforted by this.
- Changes may be due to a number of things. Most often the reason for this is the disease produces chemicals that affect how the brain works. As death approaches, the ability to think and communicate weakens and eventually stops.

## YOU MAY NOTICE THE PERSON:

- Becomes restless, excited or irritable at times for no apparent reason.
- Is easily distracted and is unable to follow simple directions, think clearly or communicate.
- Is unable to remember things or recognize familiar people or objects.
- Seems drowsy all the time and falls asleep even when you are talking.
- Is more difficult to arouse or waken.

## COMFORT MEASURES:

- Sit quietly to provide a comforting presence.
- Reduce confusion by limiting distractions such as TV, radio or too many visitors.



- Gently bring the person to reality with reminders about where they are, who you are and what time is it, etc.
- Do not argue if the person's reality is different. Sometimes going along with someone who seems mildly confused allows the situation to pass without upset.
- Quietly listen to the person, who may need to express some thoughts, worries or feelings. Get close and talk gently.
- Use touch to connect with someone who is unable to respond. Soft music may be relaxing. Assume the person can hear everything you say on some level.
- Talk to someone about relaxation techniques for the person, yourself, and family members.



# CARE FOR THE SPIRITUAL ASPECT OF THE PERSON



## SPIRITUAL NEEDS

All people have spiritual needs. This may be especially so near the end of life and in those who are struggling daily with conditions that are incurable.

**A Terminally ill person may have some or all of these needs:**

- Finding meaning in life and illness
- Having a sense of control
- Forgiving self and others
- Looking back on life events and accomplishments
- Saying good-bye to loved ones
- Religious
  - making peace with God/the Creator
  - making peace with others
  - readying oneself for the afterlife
  - taking part in the rituals of the person's church or spiritual community



**A person might ask some or all of these questions:**

- Who is God/the Creator?
- What have I done?
- What is the meaning of my journey?
- What will I leave behind?
- How can I understand that death is coming?
- Who and what is important to me?
- Is there forgiveness and love?
- What does it feel like to be leaving this life / world?
- Where will I go?
- Will I see my family again?





## What Helps:

- Letting person talk about their questions, and listening to the feelings behind the words. Questions you might ask:
  - Who do you have in your life to be with you at this time?
  - What is it like for you now?
  - What is concerning you most at this time:
  - Do you have beliefs or a faith that is helpful to you now?
  - What does the future look like for you? ◇
- Speaking positively, providing reassurance
- Looking at pictures
- Talking about old times, asking about special skills
- Reading books, poetry
- Sharing music
- Viewing nature
- Talking about rituals that are important, and asking the appropriate person/people to perform them
- Prayer or meditation
- Silence
- Sitting and ‘keeping watch’ or ‘being present’ with the person



## Letting Go

At the end of life, some people may need help letting go. Each person is unique with their own spiritual needs. They may need silence, talking, praying, or rituals. They have to work on letting go before the spirit can break free.

## **Spiritual Problems**

Some people struggle with religious or spiritual concerns at the end of life. If the person or family is having trouble with these concerns, it may be helpful for a leader from the appropriate spiritual tradition, for example, an elder, priest, minister or spiritual leader to speak to them.

## **Decision-making**

A person's spiritual or religious beliefs may affect the decisions they make about their care—for instance, whether they wish to stop treatments. If the person or their substitute decision-maker, family, and health care workers can talk about these beliefs, it may cut down on misunderstandings and conflict at the end of life and provide comfort to the person and family.

## **Differing Beliefs**

It is important to respect whatever the person and family believe and find comforting. Sometimes the person and other family members do not have the same spiritual or religious beliefs. The person's beliefs and wishes need to be carried out. But family members' varying beliefs need to be respected. They may find it helpful to seek additional comfort for themselves from their own spiritual advisor.

***“We are not human beings having a spiritual experience, we are spiritual beings having a human experience”.***

Pierre Teilhard deChardin

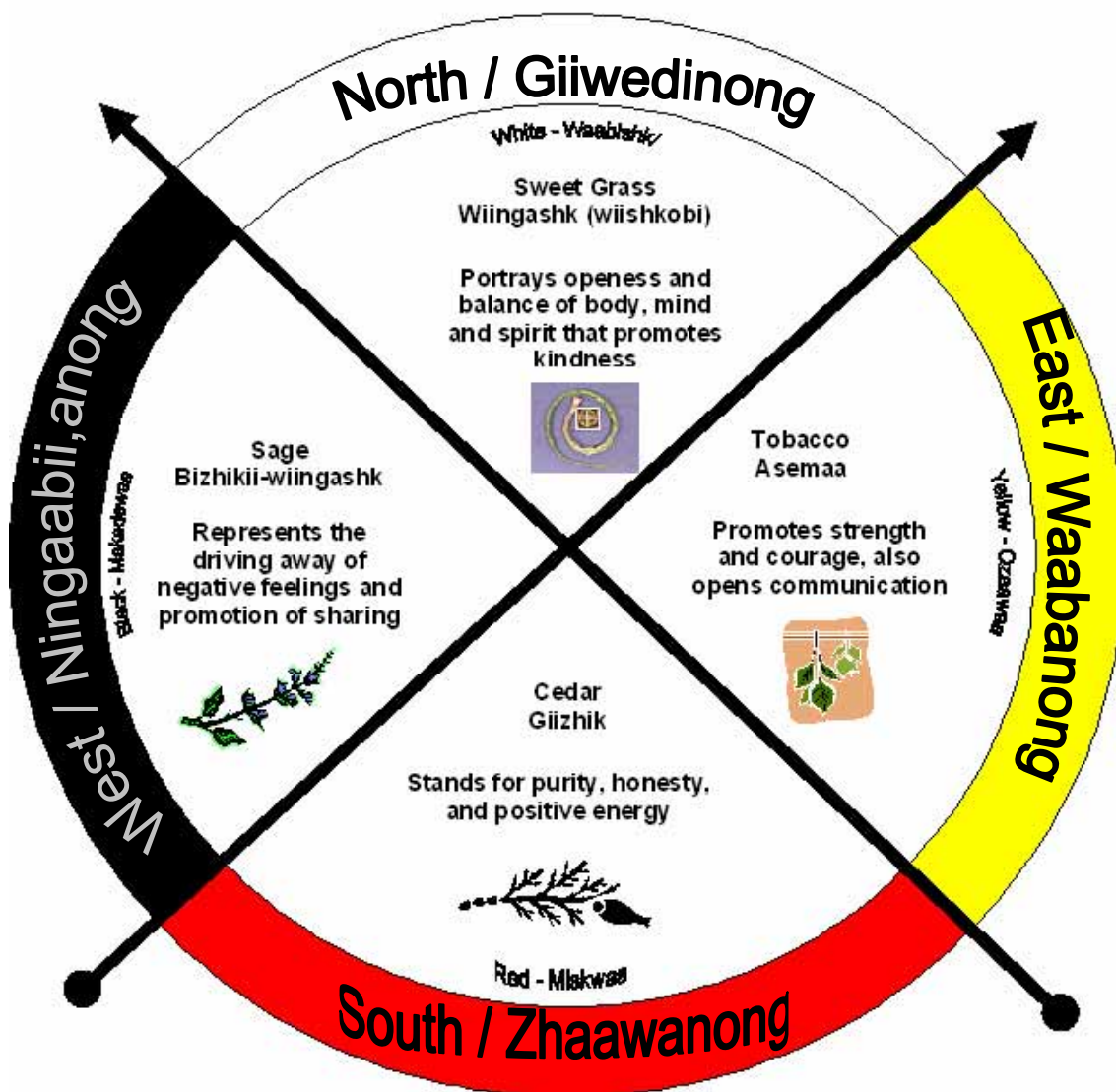
♦ adapted from “Adam B. Cohen, PhD, & Harold G. Koenig, M.O. “Spirituality in Palliative Care”  
<http://www.geriatrictimes.com>

♦ adapted from Charles Hayter and Sharon Grant “A Guide to Spiritual Care of the Caregiver”,  
supplement to Hot Spot, volume 3 issue 2. May 2001

# Aboriginal Customs



# Four Directions



*Josephine Potson*

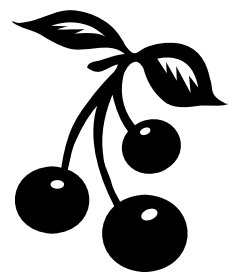
Josephine Potson

# Aboriginal Symbols, Practices and Customs

There are many symbols, practices and customs, some of which are well known to many people and some which are known only to a few. The following is a list with brief explanations about each. To achieve full understanding of some of these symbols and practices, one must personally experience them or be led to enlightenment through traditional teachings of an elder. The explanations for the items are therefore brief and are intended to provide a broad overview of things that may have different meanings to people of different cultural backgrounds.

## Protocols on Approaching Elders

- The first step is to bring a Tobacco offering to an Elder of your choice.
- Next wait for the Elder to say to continue or wait for him to light up the pipe he/she carries.
- Then he will let you know when to begin to say what brought you to him.
- Sometimes they will ask you what is wrong or what brings you to them, before they light up the pipe.
- When this is done, it is to see if they are the right person or not.
- Mostly your intuition is what guides you to the person that you are meant to see.
- The Elder will then give you direction as when to come back if he/she needs time to ponder.
- If the need is immediate they will tend to you right away.
- It is always wise to be prepared for that situation



- Personally when visiting an Elder, I always bring Tobacco, miichim (food-berries, wild rice, or wild meat) and gifts.
- Depending upon what your situation is – a naming or healing ceremony, personal guidance - the Elder will let you know when to come back if not immediate.
- The paagichigaanan (gifts) are given from the heart – how much or what its worth to you for your personal well-being.
- If follow up visits are required for treatment, consultation, guidance, you would do the same as if it was your first visit.
- The guidance, consultation, and treatment are what the Medicine person does for you for your healing. For that to continually work for you, you have to follow the instruction given to you.
- When people say that the medicine doesn't work, it is because they don't believe in the medicine or they don't follow the instructions given.
- Sometimes the medicine given has to get the sickness out. This is when you will experience sweating, vomiting or other means of being expelled.
- If you are unsure of the instructions, directions or task you must do; ask the person that you are seeing.

### **Some traditional practices and customs:**

#### **Sweat Lodge Ceremony**

The Sweat Lodge Ceremony is a place where cleansing and healing takes place. It is said that it is a sacred place. It represents the womb. When we enter



the sweat lodge to share our sorrows, hurts, anger, illnesses are taken from us. The cleansing and healing takes place, when we let go of these negative feelings. When we leave the sweat lodge we are reborn, cleansed.

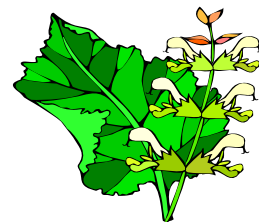
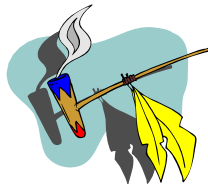
- Each sweat lodge keeper has his/her own teachings. Each individual sweat lodge is to be respected. The fire pit area is to be used ONLY for the sacred fire during the Sweat Lodge Ceremony.
- When the Sweat Lodge Ceremony is completed and the rocks are cooled, usually the next day, the rocks and cedar are taken away to a designated area.
- The sweat lodge area is to be respected and kept clean.

### **What to wear when going to a Sweat Lodge**

- A man wears shorts
- A woman wears an ankle length gown
- Each needs a towel to use.

### **What to bring when going to a Sweat Lodge Ceremony**

- Tobacco
- Food
- Gifts



### **The Cleansing Ceremony**

We cleanse:

- Our eyes so that they will see truth around us.
- Our ears so that we will hear the spiritual truths given to us by our Creator. So we can listen to the truth as the Creator, the Grandfathers, the Four Directions and the Four Kingdoms share it with us. Be open

to the request for assistance from others. Cleansing our ears allows us to hear only good things and lets the bad things bounce off.

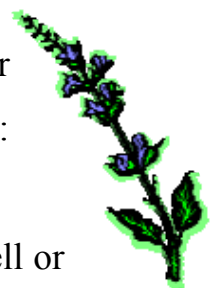
- Our hearts so that our hearts will feel the truth. So it will grow with us in harmony and balance and be good and pure, as well as, be open to showing compassion, gentleness and caring for others.
- Our feet so that our feet will seek to walk the true path to seek balance and harmony and lead us closer to our families, friends and community. We also cleanse so that we can walk closer to our loved ones and help us flee our enemies and lead us closer to our Creator.
- Our mouth so that all we speak will be truthful. So that we speak in a way that will empower the positive, speak only of good things and always full of words of praise and thanksgiving for our Creator.
- Our minds so that we have a clear mind and we do not have any negative thoughts, only good and positive thoughts.
- Our spirit so that we are open and receptive to communication with our Creator.



### **How to Cleanse:**

Using sage, sweetgrass, cedar or tobacco, singly or in combination or other Medicine Wheel herbs; a shell or bowl; a fan or feather and matches:

1. Mix the plants that you will be using, together. Place them in a shell or sturdy bowl and light them.
2. When they are burning use a feather to fan the herbs.





3. Once the herbs are smoldering draw the smoke from the bowl over your heart, then over your head, down your arms, over the front of your body, then down your back to the ground.
4. After you have cleansed yourself, hold the bowl for others to cleanse themselves or pass it on to them.
5. Before or after people have cleansed themselves, cleanse the area that you will be using.
6. Cleanse the sacred items you will be using.



### **Other Methods of Cleansing are:**

- Cleansing your self by submerging in water 3 times, once for yourself, once for your family and once for your relationship with the Creator.
- Cleanse yourself with sound, by using a rattle or a drum. Begin at your head and go all the way down to your feet.

### **Saagakinigaye Ceremony**

- It is a ceremony that takes place after the funeral, usually after a period of mourning.
- The period of mourning is anywhere from eight days to a year, depending on instruction given.
- The ceremony is where the deceased persons belongings are given away and something is put in the bush
- This is done so the deceased person has clothes, food and tobacco where they are now.
- Then the mourning period is over, so now we can carry on with living.

## **Additional symbols, practices and customs**

Bear Claws



Are symbols that represent healing. The people who acquire these usually have to work hard for them. They also represent a medicine person as a helper in the healing process.

Elders

Are people recognized in a community as an “elder”. These people are recognized as having experience in life and tend to be the more matured people who are held in high regard.

Fasting or  
Vision Quest

Is a ceremony in which a person would forego certain necessities in life, such as food, in search for answers to one’s questions. The answers may appear to the person in a dream

Feathers



Usually eagle feathers represent strength and courage and tend to be highly respected by those who understand the significance of this bird. To acquire a feather people need to work hard for them.

Four Directions  
Teachings

Are teachings that represent traditional values, beliefs and ways of life.

Initiation

Is a ceremony in which people respond to a calling and are recognized in a form of “rite of passage”

Medicine  
Bundles

Include various articles that assist in the healing process.

Medicine  
Practices



Are various forms of healing that take place utilizing various herbal / root medicines and spiritual ceremony.

Medicine Men /  
Women



Are people who have learned to utilize various medicine practices.

Medicine Wheel



This is a way of presenting concepts about traditional teachings.

Metis Sash



Symbolizes togetherness, looking after each other, maintaining a nation and caring for one another.

Pow-Wows



Are primarily forms of entertainment, whereby people dance to the sound of a drumbeat. For some people, pow-wows have a spiritual significance.

Shake –Tent

Is a ceremony in which people with questions of all sorts can receive answers.

Sunrise  
Ceremony



Is a gathering of people to greet the sun in the morning as it rises to begin a new day and to give thanks for another day of life.

Sweat Lodge



Is a place where people can participate in cleansing or healing ceremonies where water is poured on hot rocks to produce steam.

Sweetgrass



Is a medicine used for purification and represents kindness.

Talking, Sharing  
or Healing  
Circles



Ceremonial gatherings where people come together for the purpose of talking, sharing or healing. What is shared in the circle stays in the circle.

The Midewiwin  
(The Original Way)

A spiritual way of life in which Mide people aspire to live according to the original teachings

Tobacco



A medicine used to communicate in the Spirit World. The smoke represents one's visible thoughts.



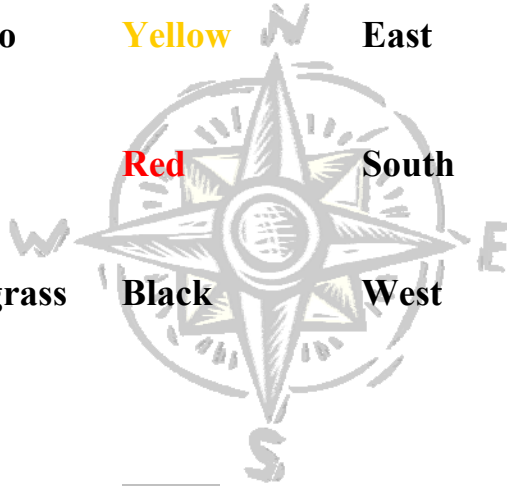
Opening a window and putting some tobacco out the window represents helping the person who has left us on the journey to the spirit world.



A piece of birch bark is used as a light for the person not to re-enter a home that the person has left (suggested to home aged workers) to be placed at windows and doorways.

## The Sacred Plants

<u>Sacred Plant</u>	<u>Colour</u>	<u>Direction</u>	<u>Description</u>
Tobacco	Yellow	East	A gift of the spirit that promotes strength and courage.
Sage	Red	South	A medicine of the plants that promotes sharing.
Sweet grass	Black	West	Mother Earth's hair, braided. It represents the coming to one and balance of the body, mind and spirit while promoting kindness.
Cedar	White	North	A medicine of the trees that promotes honesty.



## Use of Sacred Plants:

- Medicines come to you when you are ready to use them in the right way.
- A woman on her time may not pick sweet grass.
- Women on their moon cannot touch any medicine, plant or herb except for sage.
- In some places a woman on her moon time is asked to remain outside the circle during ceremonies because she is on her own personal ceremony. In others she may sit inside, but not partake of the sweet grass.
- If uncertain, seek out an Elder and ask for guidance.

## **Feasting of Sacred Items**

### **Sacred Items:**

- Items a person holds dear and has a spiritual or sacred value, such as an eagle feather either given or found.
- Stones or rocks found or given in a ceremony, for personal protection or teaching rocks.
- The Anishinabe name needs to be feasted in order to acknowledge the spiritual protection and help it gives.
- Colours, dreamed and/or given in ceremonies.

### **Food:**

- Miichim (food) is offered to the spirits as well as tobacco and gifts for the help and protection provided by these sacred items.
- The food offered is berries, wild meat and wild rice offered in spirit dishes

### **Spirit Dishes:**

- Are made of birch bark, cut and made into little dishes.

### **Giveaway Items:**

- Paagichiganan are blankets, towels, shirts, socks and food items such as tea, coffee sugar etc.
- Handmade items such as blankets and shirts that are valued because of the personal time and effort put into making it by the individual
- All gifts are accepted and appreciated because it is given as a giveaway item even if it is bought or made.

## **The Dream Catcher**



- The dream catcher was used by the woodland Indians and was hung in the lodge
- Its use was to catch all dreams, good and bad.
- The bad dreams would get caught up in the webbing and be held there till first morning light, then burned off.
- The good dreams were caught but knowing their way to the hole in the center, would filter down into the feathers and be held there only to return another night, to be dreamed again.

## **What's in a native name?**

- Anishinaabe or Indian names are a link with the natural spirit world.
- To get an Indian name you have to know of an Elder who is capable of giving names.
- Once you know of an Elder who can, you must bring them an offering of tobacco. If they accept then they will give instructions as to the procedure that will be taken. They will tell you when and where, what to do, and what you will need to bring.
- When a person is given an Indian name, they are given something that comes from the earth, an object, colours or both.
- The Anishinaabe or Indian name given is to be used when introducing yourself or when praying.

- Years ago when a child was about to be born, the grandparents knew what the name of the child was going to be, thus able to understand the meaning of the name.
- The traditional teachings were followed, observed allowing ourselves to be closer and in tune with nature.

## Clan System

- As Ojibwe people, we follow the paternal line for our clan system. (i.e. an Anishinaabe man from the caribou clan marries a woman from the bear clan, their children will belong to the caribou clan.)
- In tradition, when a caribou clan member meets a fellow clan member from another First Nation, they are considered family and treated as such. That is why traditionally clan members do not marry clan members. It is considered like marrying your brother or sister. That is why, when you meet an Elder in Ojibwe country they say “wenen kii dodem” – “Who is your clan?”
- In respect, for other Anishinaabe tribes, others follow the maternal line.
- In clan system, maternal or paternal, both respect the women for they are the life givers.



## Sacred Bundles

- When a child is born he/she is given an Anishinaabe name, along with an object, colours or both. This is the start of his/her personal bundle.



- As the child grows he/she is being taught the teachings according to gender. The parental teachings needed to raise their children in a safe, respectful manner.
- In these teachings, sometimes objects are given as reminders adding to the bundles. These additions or sacred items continue throughout the years.
- The community bundle is given to an organization that helps other people. An Elder usually starts it. Also this bundle grows, as more sacred items are given, to be used in helping the community. The bundle keepers are usually the workers in the organization who respect the traditional ways. These ways need to be passed on to others

# When Death Is Near

Birch – Wiigwaas



The bark of the tree is used for a variety of things by the Anishinabe. Things like baskets, for canoes, for wigwams, teepees and for burial rituals.

It is said that when it is used for covering the grave with the inside out and secured with peeled logs all around, it becomes a home for the person that has gone on into the spirit world and sometimes returns to check its home.

Traditional medicine use;

- An infusion of the inner bark was used as an enema
- A decoction of the bark was used to treat blood diseases
- A compound decoction of the root bark was used as a gastrointestinal aid.



# When Death is Near

No matter how much we prepare or no matter what we expect, the moment of death will arrive in its own time and in its own way. The experience of dying is different for every person and for every family. It is important that you do whatever you and the family feel will help during this final stage. The following information may help.

## Plan Ahead

- Know what the person's wishes are. The person and family may decide to make funeral arrangements ahead of time.
- Ensure that affairs are in order
- Find out who to call when the death happens. It is important to talk about who will pronounce the person and sign the death certificate before death occurs. It is not necessary to call the ambulance or the police.

This will help in the following ways:

- Ensures that the person's wishes are known and respected.
- Reduces the number of decisions that will need to be made right after death.
- Provides an opportunity to talk about arrangements, concerns and feelings.
- Allows for affairs to be in order for those left behind.
- Reduces family stress during the early time of grief.



## Signs that Death is Near

**Sleeping:** The person may spend more and more time sleeping and may it be harder and harder to wake up the person. This is a normal body change.

**Help by:** Sit with the person; hold his/her hand, but don't shake it or speak loudly, speak softly and naturally. Spend time with your loved one at times when he/she is more alert or awake. Avoid speaking about the person in his/her presence. Speak to him/her directly even if there is no response. Never assume that he/she can't hear; hearing is the last sense to be lost.

**Confusion:** The person may seem confused about the time, place, and identity of people around him, including close and familiar people. This is also due in part to body changes.

**Help by:** Identify yourself before you speak, rather than asking the person to guess who you are. Speak softly and clearly.

**Restlessness:** The person may make restless, repetitive movements such as pulling at the bed linen or clothing. This may be due to less oxygen going to the brain.

**Help by:** Don't interfere with or try to restrain these movements. Speak quietly and naturally; lightly massage the forehead; read to the person or play soothing music.

**Eating and Drinking Less:** Although this is a normal part of the dying process, it is often a difficult time for family and friends. It is important to talk about feelings and fears. Do not force the person to take food or fluids. The body prepares naturally for death with the organs shutting down and not working well.

**Help by:** Feeding them may increase the person's discomfort. Keep them comfortable by giving them the food and fluids they want and keeping their mouth moist with gentle mouth care. Hunger is rarely felt. The natural processes respond to taking in

fewer fluids by the person having fewer problems with swelling, congestion and the need to get up to go to the bathroom.

See the “**Food for Thought**” pamphlet (attached) for more details. Please feel free to copy and share this pamphlet.

**Coolness:** The hands, arms, feet and then legs may become cooler to the touch. The face may be pale, and the feet and legs a purple-blue mottle colour. This indicates that the blood flow is decreasing to the body’s extremities and is being saved for the most important organs

**Help by:** Keep the person warm with blankets, using just enough to keep him comfortable. Avoid using an electric blanket.

**Lose of control of bladder and bowels:** The person may lose control of bladder and bowels as the muscles in these areas begin to relax when death is very near.

**Help by:** Find out about appropriate padding, and/or use of an incontinence product.

**Congestion:** There may be loud gurgling sounds coming from the person’s throat or chest. This is because the person is unable to swallow saliva, and doesn’t mean she/he’s uncomfortable.

**Help by:** Avoid suctioning, as this may cause sharp discomfort. Turn the person’s head to the side and allow gravity to drain the saliva. You can wipe the mouth with a moist cloth.

**Changes in Breathing Pattern:** Breathing may be irregular and may stop for 10 to 30 second periods. He/she may experience periods of rapid, shallow paint-like breathing. After death there may be a “last sigh” or gurgling sound. These common patterns are due to decreased blood flow to the internal organs.

**Help by:** Raising the head of the bed or turning the person to the side. Hold the person’s hand and speak softly.

**Decreased Urine:** Urine output normally decreases and may become tea coloured or concentrated. This is due to the decreased fluid intake as well as a decrease in blood flow to the kidneys.

**Help by:** Ask your health care provider if anything needs to be done.

**Withdrawal:** The person may seem unresponsive, withdrawn or in a comatose-like state. This shows preparation for release, and the beginning of letting go.

**Help by:** Since hearing remains all the way to the end, speak to the person in a normal tone; identify yourself by name when you speak; hold the person's hand; say whatever you need that will help him/her to let go.

**Decreased Socialization:** The person may want to be with just a few or only one person. This is a sign of preparation for release. If you are not part of this, it doesn't mean you are not loved or are unimportant. It means you have already fulfilled your task with the person; it's time for you to take leave and let go.

**Vision-Like Experiences:** The person may speak or claim to have spoken to a person already dead, or to see places/people not visible to you. This isn't a drug reaction or hallucination. The person is detaching from this life, and is being prepared for the transition so it will not be frightening.

**Help by:** Accept what the person is saying. Avoid explaining away or arguing. The experience is real to your loved one and is normal and common.



## **How Will You know When Death Has Happened**

- Your loved one will be entirely unresponsive.
- He/she will not be breathing.
- The pulse and heartbeat will stop.
- Your loved one's eyes will be fixed in one direction; they may be opened or closed.
- Loss of control of bladder or bowel may occur
- There will be no movement
- The person's mouth may be open and their jaw may be slack
- There will be no pain

## **What to Do if You Think Death Has Happened**

### **Comfort Measures:**

- Remain calm.
- Allow tears and feelings to come.
- Breathe deeply and encourage everyone to do the same.
- Allow everyone to be in physical contact with others, i.e., hug, hold hands or link arms.
- Gather around the person to send blessings and love, in silence or speaking aloud.
- Ceremonies or prayers according to tradition.
- Warming drinks may help.
- Reassure the family they can do whatever feels right for them.
- Call family and health care providers according to the plan.





- **Do not call 911**, the police, or the fire department. These calls are not necessary when the death is expected.
- **Call the person who will pronounce the death.** It is important to talk about who will pronounce the death and sign the death certificate before death occurs.
- Please know that there is no right or wrong way to be at this time. Do what you feel is right for you and not what you may feel is expected of you.
- Allow everyone as much time as they need to take leave and let go. For some this may be hours, while others may not wish to stay. You or family members may want to wash and dress the person, and attend to any rituals that are important to the family.
- **Do not be afraid** to touch, hug or kiss the person. Some people may wish to lie down beside him/her. These reactions are normal. Please be aware that others may have needs which are different from yours, so be sensitive to and supportive of their special concerns.
- **Crying** is a personal reaction. For some this is a natural reaction to grief. Others may internalize their feeling and may not be able to cry. This doesn't mean that one grieves more than the other; both reactions are normal.
- **Prayer:** For some prayers are very important, but unnecessary for others. Be guided by your inner self and do what is right for you.
- **Cultural rituals:** It may be necessary for you to attend to special cultural ceremonies or prayers according to tradition at this time.
- **Spirituality:** For some this is very important, while others may have a lesser need. Talk to the advisor of your choice

## **Caring for Yourself**

Seeing your loved one dying can absorb all your energies. If the process is a long one, you are at risk of becoming mentally and physically exhausted. Please know that your well being is as important as that of the dying person. In fact, one of the best things you can do for your loved one just now is to care for yourself. Both you and the dying person may experience feelings of frustration, guilt, sadness or anger. These emotions are common and normal. They occur in response to the losses you are now experiencing.

**Help by:** paying careful attention to attend to your needs:

- **REST:** Sleep may not come easily, but do try to get adequate rest.
- **Nutrition:** While you may not feel like eating, do attend to your nutritional needs.
- **Time for Yourself:** Time away from your loved one is essential if you are to avoid mental exhaustion. Ask other family members or friends to stay with the person to give you an opportunity to re-energize.

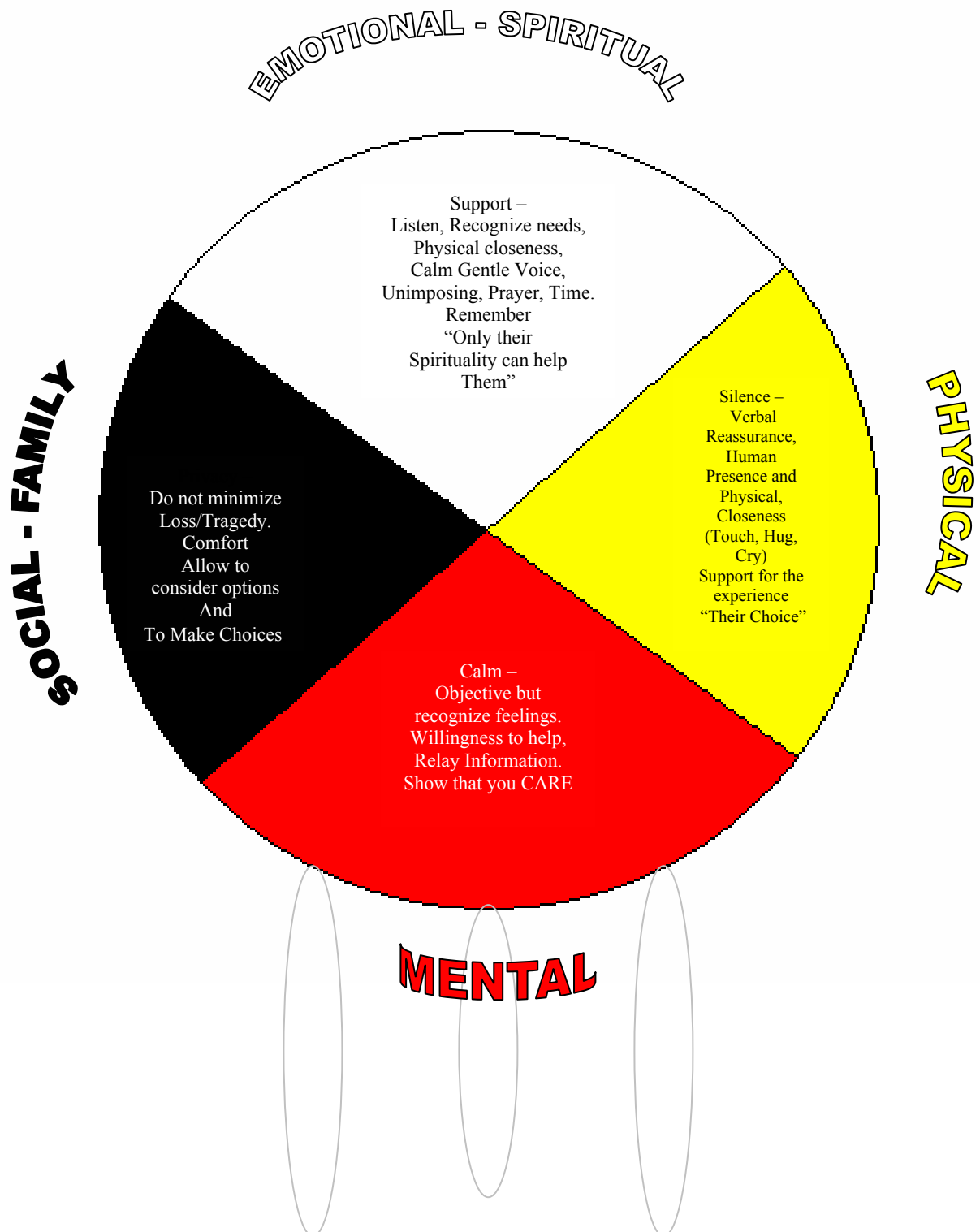
***Remember, there is no perfect way to care, be guided by your love for the person.***



# GRIEF



## MEDICINE WHEEL RESPONDING TO GRIEF



\*\*Revised with permission by: Rosella Kinoshameg

**Grief:**

The natural reaction to loss is grief. It is part of a normal healing process, which is common to most cultures and people. There is no set time frame for grieving and it varies from person to person. For example, some people may experience intense grief while for others it will be mild. For some, grief begins immediately after the death while for others it happens later. In some cases grieving can last a short time while for others it goes on for year. And some people may grieve privately, while others are more public about their grief.

The kind of grief a person experiences can be affected by:

- Relationship to the person
- Adult and childhood experiences with loss
- Degree of dependence on the person who died
- Age and gender
- The type of death (sudden or prolonged)
- The condition of the body (disfigured)
- The quality of the relationship to the person before the death (i.e. positive or negative)
- The need to hide feelings
- Social support
- Religious beliefs
- Other life crises before the death

## **How People Express Grief:**

When someone important to you dies, you grieve. You may experience a lot of different emotions and behaviors. These may be very different from those of other people. This is normal. Different people grieve in different ways. Your emotions and behaviors will probably change over time. This, too, is normal. Grieving takes place over an extended period of time, and there are different feelings that go with early, middle and later grief, although often people go 'back and forth' between these stages.

### **Early Grief—When a death occurs (walking the edge)**

As you accept the fact of the death of someone important, you will feel shock, numbness and disbelief that this has happened. Panic and strong physical and emotional reactions are common:

shortness of breath and heart racing or pounding

upset stomach

low energy, weakness and restlessness

crying, sobbing, wailing

indifference, emptiness ("can't feel anything")

outrage and helplessness

confusion, forgetfulness and poor concentration

denial and daydreaming

continually thinking about the person who died and/or the death

blaming God or life

lack of meaning, direction or hope

wanting to die or join the person who died

withdrawal from others

unrealistic expectations of self and others

poor judgment about relationships

What helps:

pace yourself moment to moment

make no unnecessary changes

talk about the person and the death

let other people help and support you

### **Middle Grief–Adjusting to Loss (entering the depths)**

Later, as the numbness goes away, you will deal with what this loss means to you and the pain of grieving. The strength of feeling may surprise and frighten you, but it is natural and you will move through it.

You may experience:

changes in appetite and sleep

shortness of breath and racing or pounding heart

upset stomach

very strong and conflicting emotions

increased fear for self or others

anger, sadness, guilt, depression

sense of going crazy

problems remembering





problems with concentrating or understanding  
vivid dreams or nightmares  
trying to contact the person who died  
feeling the presence of the person who died; visitations from them  
continued lack of meaning  
rushing into new relationships  
wanting company but unable to ask  
continued withdrawal and feeling alone  
feeling self-conscious

What helps:

recognizing and expressing feelings  
admit changes  
understand grief and know others have feelings and experiences like yours

### **Later Grief–As Life Goes On (mending the heart)**

As you adjust to life without the person who died, you will begin to re-connect with the world around you. You have more energy for family friends, work and other interests. You may experience:

physical symptoms go away  
sleeping and eating are more settled  
gut-wrenching emptiness begins to go away  
emotions are not so strong

feeling of coming out of the fog  
more peace; less guilt  
concentration and memory get better  
less dreams and nightmares  
reconnect with religious/spiritual beliefs  
life has new meaning and purpose  
acceptance of death as part of life  
more interest in day-to-day life of self and others  
able to reach out and meet others  
energy for visiting and social events

What helps:

thinking about how far you've come since the death  
beginning to think about a future  
taking part in new activities  
new roles and relationships

*(Adapted from Victoria Hospice Bereavement Program pamphlet: Dealing with Grief)*

### **SOME IDEAS THAT MAY HELP** *(adapted from ©Willowgreen—advice)*

Following are some things which have helped other people when they mourned a loved one's death. Perhaps they will help you as well.

#### **Talk regularly with a friend or elder.**

This is one of the best things you can do for yourself. Look for someone who's a good listener and a caring soul. Then speak what's on your mind and in your heart.

**Recall your dreams.**

Your dreams often have important things to say about your feelings and about your relationship with the one who died. Your dreams may be scary or sad, especially early on. They may seem weird or crazy to you. You may find that your loved one appears in your dreams. Accept your dreams for what they are and see what you can learn from them. No one knows that better than you.

**Tell people what helps you and what doesn't.**

People may not understand what you need. So tell them. If hearing your loved one's name spoken aloud feels good, say so. If you need more time alone, or help with chores, or a hug, be honest. People can't read your mind, so you'll have to speak it.

**Write the person who has died.**

Write letters or other messages to your loved one, things you wish you could say if they were present. And who knows but what they're not present in some way? Keep what you write or throw it away. You'll find this urge to write will go away, but for awhile it can be a comfort.

**Use your hands.**

Sometimes it help doing things with your hands which you don't have to think about very much, like knitting, crocheting, carving, woodworking, polishing, jigsaw puzzles, painting, braiding, beading, etc. etc.

**Do something your loved one would enjoy.**

Remember the one who died in your own way. There are probably a hundred different things you could do that once brought meaning and satisfaction to the one you loved. The meaning and satisfaction don't have to end with the death of that person.

**Change some things.**

As soon as it seems right, change some things in your home to make clear this change that has happened. Rearrange a room or replace a piece of furniture or give some items away that will never be used again. This does not mean removing all signs of the one who died. It does mean not treating your home or loved one's room like a shrine

which cannot be changed in any way. For some First Nations people, it is a tradition to make changes or renovations to their home after a loved one has died.

**Allow yourself to cry.**

Crying goes naturally with grief. Tears will fall when you least expect them. Quiet sniffles can become huge sobs on a moment's notice. This is not unusual for a grieving person. If you feel like crying, then cry. If not, then don't. Some grieving people seldom cry—it's just not their way.

**Engage your Soul.**

You'll want to do this in your own way. Some people meditate, some pray, some spend time alone in nature. Some worship in church and others do it on their own. Some consult a spiritual leader. Many grieving people begin to sense that all of us, living and dead, are connected on a spiritual level in a way that can't be explained. Include your soul as you grow through your grief.

**If appropriate for you, use First Nations traditional grieving practices.**

For example, one of the Anishinabe's grieving practices is to have a feast in memory of their loved one in any of the four seasons. Food is offered to the sacred fire to help the loved one's journey in the spirit world. If you wish, speak to an elder for guidance.

**HOW YOU CAN HELP SOMEONE WHO IS GRIEVING**

Reach out to the person.

Be there for them.

Encourage the person to talk about the death and the funeral.

Give the person permission to grieve.

Remember you cannot take away the pain.



Be yourself and show concern.

Plant the seeds of hope.

Let the person know you believe that the tasks of mourning will be completed and the pain will get better.

Allow the person to cry, talk and talk and review and review.

Encourage the person to be patient and not expect too much of themselves.

Let the person know your understanding of the pain and their wish to avoid it.

Encourage the person to give themselves a 'break' from grieving.

Suggest physical activities to release emotions.

Help the person deal with practical problems that come up.

Encourage the person to look after their own health.

When appropriate, encourage the person to find rewarding things to do and people to build relationships with.

Do not push the person into new relationships until they are ready.

Don't let your own needs get in the way.

Don't tell the griever to feel better because of loved ones still alive.

Respect the person's beliefs and traditions, no matter what they are—for example, Christian, traditional, or a combination.



# Finding Your Community Care Team



# DEATH

## Choosing a Place to Spend the Last Days

### Going Home



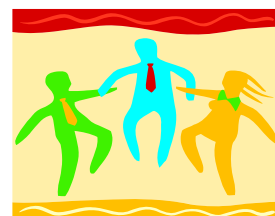
Palliative care honours the person's choice. When a person is faced with a life threatening illness there are many choices they and their family will make.

As things begin to change, the person may be thinking about returning to their community and home to spend their last days with their family and friends.

### Planning for Care at Home

Palliative Care is a community affair. It involves many different people and each community is different. If the choice is to be at home it is important to plan for care ahead of time. Part of this planning is to find, who can provide care and how care can be provided in the home community. For example, what resources such as equipment are needed and available before the person returns home?

In First Nations Communities, someone is always around to help.



### Communication and the Team

Before discharge from hospital, or on return to the community, a meeting between and among, the person (if well enough), the family, community and the medical people, can be helpful. This meeting can take place in person, by telephone, or teleconference, with the aim of developing the plan of care.

When this group meets, be sure to include a translator if the person or family members are not comfortable expressing themselves in English. If possible, the translator should not be a family member.

## Finding the Community Care Team

Hospice palliative care uses a team because the help provided may be very involved and often cannot be carried out by one person.

The palliative care team is a group of people who work together with a common purpose - to help the dying person spend their last days as they choose.

Each care provider is a valuable member of the team. **The person and their family are the most important members of the team.**

Some people who might be helpful as part of the team are: family members, friends, elders, the nurses at the nursing station and in the community, the homecare coordinator, case manager, homecare workers, Community Health Representatives Mental Health Counsellors, Doctors, spiritual caregivers, and traditional healers. Others such as Band Administrators, Health Directors, Social services, legal advisors, Funeral Director, and Emergency Services workers can also be helpful. Palliative care providers from other areas may help with difficult situations, either by phone or video conferencing.

It is important to find the gifts each member brings to the team, in the home community and from neighbouring communities and larger centers.





## Why the Community Team Needs to Meet

When the person is at home and the plan is set, meeting regularly with the team to talk about how things are going and adjusting the plan helps to prepare for changes as they come along. Some reasons to meet may be:

*To talk about goals of care.*

An example of a goal of care is the person's wish to spend their last days at home in comfort even if they are very sick.

Asking these questions may help to make decisions:

- ❖ Why are we doing this?
- ❖ Is it what the person wants?
- ❖ Will it make them more comfortable?

*To solve problems as they come up.*

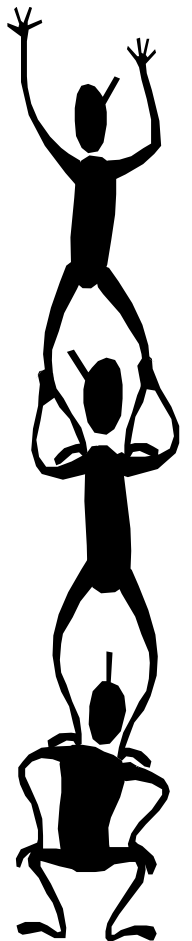
*To work out differences between and among the family and providers*

*To prepare everyone for changes:* For example, what to expect as the illness progresses and how to provide specialized care if it is needed. What is needed to help the providers learn more?

*To plan for crisis:* For example, what if the person has bad pain in the middle of the night - who do we call?

*To provide support for one another at this difficult time.*

*To keep communication channels open.* Sometimes written communication notes or an In-Home Chart may be able to be used to pass messages between and among the team, but meeting face to face is important.



*To prepare the care team and family for when death happens.*

It is important to talk about the following before death occurs:

- What to expect when death happens;
- Who will pronounce the person;
- Who will sign the death certificate and
- Who the family will call.

The plan along with the numbers to call should be written down and shared with the family and the care team.

It is not necessary to call the ambulance or the police.

## Organizing and Planning the Care

Important Questions to Help Direct the Person's Care



- Who is the leader of the family?
- Who works outside the home?
- Who is in school?
- Who is able to stay at home most of the time?
- Who can take care of practical chores?
- Who knows about care at the end of life? Are they willing to be part of the care team?
- Who will be the healthcare provider/caregiver in charge of the care?
- What is needed? i.e. medications.
- What is available in the community? i.e. ceremonies
- What additional financial resources are needed and how can they be accessed?
- Are there people from other places who know about palliative care who can support us?

As well as personal and medical needs, there are other practical needs to be met such as:

- Cleaning the house
- Cooking the food
- Doing the laundry
- Shopping for groceries
- Taking care of the children & pets
- Organizing the visitors and companions
- Ensuring needed equipment is available and in working order



Questions That the Family Member Taking Care of the Funeral Arrangements Must Ask the Person and Others:

- What kind of service or ceremonies did the person want/ does the family want?
- Where and when will it take place?
- Who will do the service? Elder? Priest? Friend?
- Who will be notified?
- Who will do the notifying?
- Will people come from out of town? Do they have a place to stay?
- Does the person want to be buried or cremated, based on their wishes and First Nations traditional beliefs?
- Where will the burial take place?
- If cremated, where will the ashes be kept?

# Seven Guiding Principles for the Team that Provides Care<sup>1</sup>

**PRINCIPLE #1:** SHARING RESPONSIBILITY IS THE KEY TO NOT “BURNING OUT”.

- ❖ no one person has to be in charge all the time
- ❖ no one person has to deal with every crisis
- ❖ no one person has to be “on call” every single day
- ❖ no one person has to try to run his own life plus the entire, complex life of his loved one
- ❖ let the others do their share. They want to. They need to

**PRINCIPLE #2:** IT WON'T WORK UNLESS EVERYONE GAINS SOMETHING PERSONALLY.

- ❖ recognize the importance of team members feeling good about caring for someone
- ❖ the person being cared for will feel too guilty unless you gain something too

**PRINCIPLE #3:** KNOW YOUR LIMITS AND STICK TO THEM.

- ❖ whatever you can do to help is enough
- ❖ if you can't or don't want to do something, don't. (Someone else is probably good at it, or loves to do it.)

**PRINCIPLE #4:** THERE IS NO ONE RIGHT WAY TO DO IT

- ❖ if there are ten members, there will be ten ways to do it
- ❖ it's okay to disagree
- ❖ agree on basics, and then follow the rules. You may learn some amazing things

---

<sup>1</sup> Share the Care, Cappy Capossela & Sheila Warnock, 1995

**PRINCIPLE #5:** ANYONE WHO WANTS TO HELP SHOULD BE ENCOURAGED

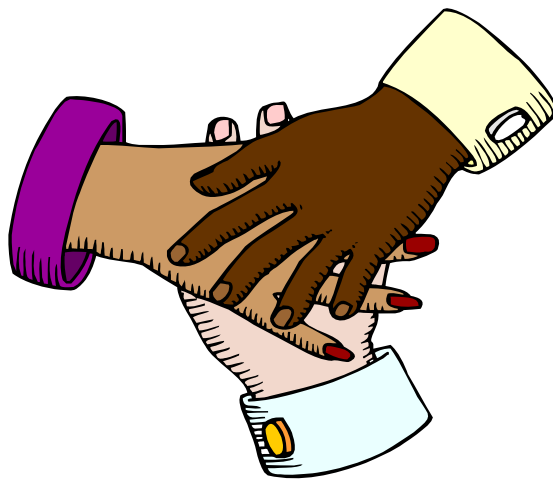
- ❖ a group needs eight, but ten is better
- ❖ if main caregivers are “real” family, they must be willing to broaden the circle
- ❖ “free-floaters” (people who can help only occasionally) are very important

**PRINCIPLE #6:** TRUST THE GROUP; SUPPORT EACH OTHER

- ❖ the group has power
- ❖ someone has the talent or the answer
- ❖ go on vacation. The others are there
- ❖ share your feelings; share the goal
- ❖ spend time together; acknowledge each other

**PRINCIPLE #7:** KEEP YOUR OWN LIFE IN GOOD WORKING ORDER

- ❖ take care of yourself, or you won’t be able to take care of the patient
- ❖ exercise, rest, stay in “life”
- ❖ lighten the rest of your load
- ❖ don’t forget about your own family and friends
- ❖ let your friends, your boss, and your own family know what you are doing



# Planning for Care

	Date/Time	Name and/or Task
Mondays		
Tuesdays		
Wednesdays		
Thursdays		
Fridays		
Saturdays		
Sundays		

Name: \_\_\_\_\_

Page Number: \_\_\_\_\_

## Communication Notes/Comments

Date and sign communication left below. Initial in the shaded area when you read the notes.

<b>Date:</b>	
<b>Read:</b>	<b>Signature:</b>
<b>Date:</b>	
<b>Read:</b>	<b>Signature:</b>

# Important Family Supports

Personal Care		
		Person's Name
1	Bathing	
2	Feeding	
3	Medications	
4	Companionship	
Housekeeping and Child Care		
		Person's Name
1	Cleaning	
2	Cooking	
3	Laundry	
4	Child Care	
5	Groceries/Shopping	
6	Organize Visitors/Companions	
7	Other	



Funeral Arrangements		
		Person's Name
1	Planner for Funeral Arrangements	
2	Other	

Other		
		Person's Name
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		
13		
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16		
17		
18		
19		
20		

# Important Community Contacts

	Name	Phone Number
1	Doctor	
2	Elder	
3	Family Members	
4	Spiritual Healer (of choice)	
5	Nursing Station	
6	Medical Clinic	
7	Community Health Representative (CHR)	
8	PSW/Homemaker	
9	LTC Community Coordinator	
10	Home Care Coordinator	
11	Band Administrator	
12	General Welfare Administrator	

## Other Numbers

1	Counselling Services	
2	Hospital	
3	Ambulance	
4	Pharmacist/Drug Store	
5	Funeral Director	
6	Expert Regional Palliative Care Team	

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<http://www.Willowgreen.com> – (with permission)

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Charles Hayter and Sharon Grant , “A Guide to Spiritual Care of the Caregiver”, supplement to Hot Spot, Volume 3 Issue 2. May 2001. (adapted with permission)

Aboriginal information reviewed and accepted by the elders are considered normal practices by the Gizhewaadiziwin Health Access Centre



# RESOURCES

- ❖ Food for Thought Pamphlet
- ❖ Food Groups
- ❖ Pain Assessment Sheet



# **Caring Connections The Pain & Symptom Management Team**

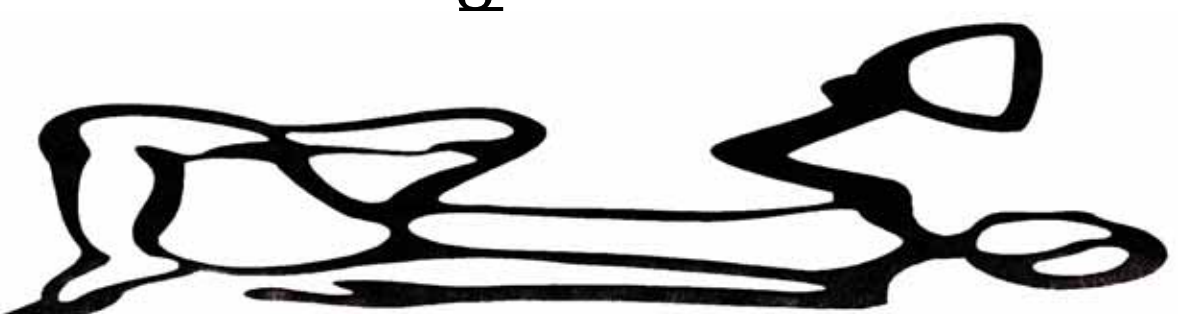
Phone: (807) 343-1625  
Fax: (807) 344-0944  
1-800-319-PAIN (7246)  
Important Numbers:



Barb Linkewich &  
The Long Term Care Education Committee  
October 1998  
This pamphlet may be copied

# **Food For Thought**

**If Your Loved  
One Isn't  
Eating!**







Are you facing the very difficult decision of whether to feed your dying loved one or not? Few situations will be more troubling.

The information offered in this pamphlet is designed to help you in your decision-making.

**Do You Know** that when the body is dying all the organs begin to shut down and work less and less effectively. For instance, the heart, brain, liver and kidneys (to name a few) are less and less able to perform their functions. The digestive system also becomes disabled, often to the point where food just cannot be digested. Your loved one will lose his/her appetite and may be troubled with nausea and vomiting. This is the body's way of showing that food is no longer necessary.

**It may help** if you can think of this as a normal part of dying. Strange as it may sound, there are definite advantages of little or no food intake at this time. This is nature's way of leading to a peaceful death.

## **Is There Anything You Can Do?**

While there are not any easy answers, you may find the following helpful:

- ♥ Avoid conflict by supporting your loved one's decision (no matter what it is).
- ♥ Discuss your feelings with family/ professionals.
- ♥ To ensure good future memories use your remaining time by: talking, holding hands, being there, looking at photo albums, giving back rubs, playing cards, reminiscing, etc.

This will provide quality time for you and will show others that you care. Losing hope, while painful, allows you to start the grieving work. Your continued support and advocacy will ensure that abandonment does not occur.



**Lung Secretions** will be less, resulting in less congestion and easier, more comfortable breathing.

**Mouth Secretions** will lessen. This will be especially beneficial if your loved one has swallowing difficulties. For example, he/she will drool less, and the need for uncomfortable suctioning will be reduced. The benefits will be an increase in comfort and dignity.

**Nausea and Vomiting** will be less and will greatly add to his/her comfort. Energy will also be conserved.

**Ketone Formation** happens when food intake is low. The importance of this is that it creates a feeling of euphoria or well-being. It works to reduce the anxiety one may feel in the face of coming death.

You may be asking **Are There Disadvantages to Not Eating or Drinking?**

Hunger is rarely experienced. However, thirst may occur initially. It is easily relieved by sipping water or sucking on ice chips or hard candy. The thirst usually disappears after the first few days.

Careful attention to keeping the mouth moist and clean will enhance comfort.

Artificial feeding can keep a person alive for a long time. However, studies show that complications may actually shorten the life span.

### **Considerations:**

Is your loved one able to make his/her own decisions? If not, does anyone have Power of Attorney for personal care? Has he/she expressed any wishes about feeding at the end?



## **What Are Your Feelings:**

You probably feel very emotional and overwhelmed by what is happening. There are valid reasons for this. In our society, we see food as a basic necessity of life. We equate it with **LOVE**. We view a good appetite as a sign of good health. Most of our social functions involve eating or drinking. You are likely to feel guilty and helpless because you are not providing a basic necessity. You may be afraid that others will see you as uncaring.

You may not know what to do with your time if you are not offering food. You may feel conflict between yourself and your loved one if your efforts to encourage eating are not successful. You may also feel conflict with the staff if their efforts are not successful. You may be losing your sense of hope as you see your loved one slipping away leaving you powerless to stop it. You may fear that your loved one will be abandoned.

## **Let's look at why:**

In most cases, pain is less. As fluid/food intake is reduced, so the tissues become dryer and shrink. This means that if there is a tumor present there is less pressure on a tumor. The tumor itself may become smaller. The need for pain medication is also less.

**Swelling** of the feet, legs and other tissues will be reduced. If fluid has accumulated in the abdomen, comfort will be promoted as there will be less pressure on the organs; breathing will also be easier.

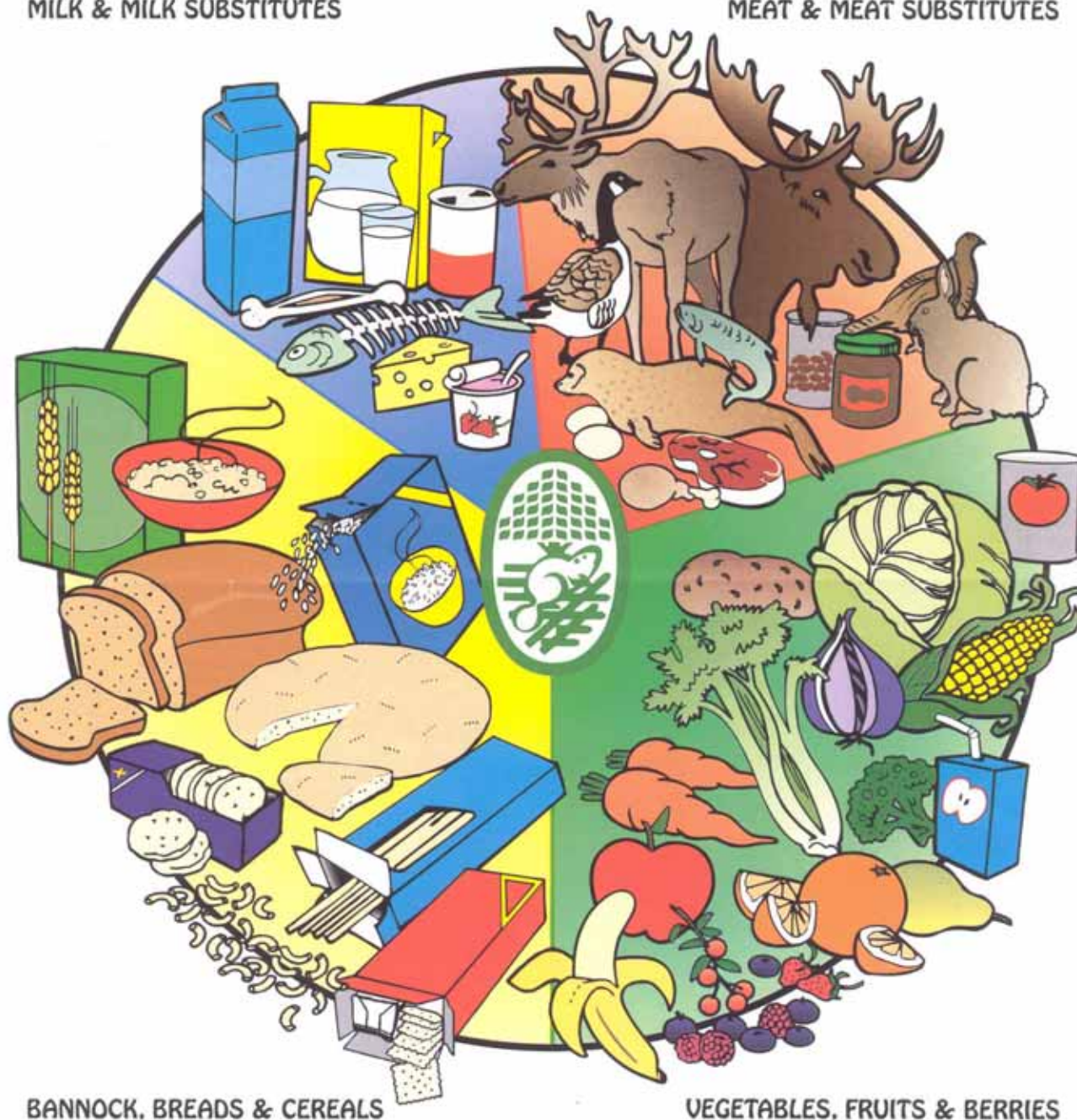
**Urine Output** will go down, meaning that less energy will be used going to the bathroom. If bladder control is a problem, it means less incontinence and a greater sense of dignity.



# EAT FOODS FROM EACH GROUP EVERYDAY FOR HEALTH

MILK & MILK SUBSTITUTES

MEAT & MEAT SUBSTITUTES



BANNOCK, BREADS & CEREALS

VEGETABLES, FRUITS & BERRIES

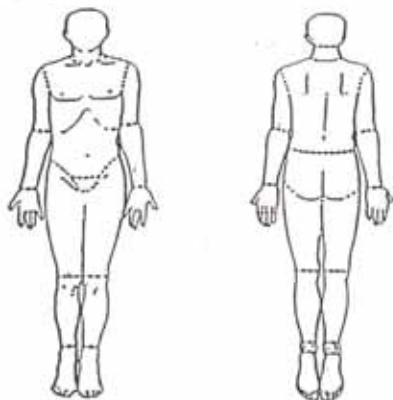


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# Initial Pain Assessment



1. Mark area of pain on the drawing – if more than one area label A, B, C, etc.

2. Rate overall pain.

Scale 0 – 10

0 (no pain)      5      severe pain (10)

at present \_\_\_\_\_ at its least acceptable \_\_\_\_\_

at its worse \_\_\_\_\_

3. How and when did the pain start?

\_\_\_\_\_

4. Pain description (Patient's words)

- |  |                                    |                                     |
|--|------------------------------------|-------------------------------------|
| <input type="checkbox"/> dull, ache                | <input type="checkbox"/> stabbing  | <input type="checkbox"/> external   |
| <input type="checkbox"/> sharp                     | <input type="checkbox"/> throbbing | <input type="checkbox"/> unbearable |
| <input type="checkbox"/> cramping                  | <input type="checkbox"/> burning   | <input type="checkbox"/> exhausting |
| <input type="checkbox"/> pins & needles            | <input type="checkbox"/> internal  | <input type="checkbox"/> gnawing    |
| <input type="checkbox"/> observed behaviours _____ |                                    |                                     |
| <input type="checkbox"/> other _____               |                                    |                                     |

5. How long does the pain usually last?

- |                                  |                                   |
|----------------------------------|-----------------------------------|
| <input type="checkbox"/> seconds | <input type="checkbox"/> hours    |
| <input type="checkbox"/> minutes | <input type="checkbox"/> constant |

6. What makes the pain worse?

- |  |                                 |
|--|---------------------------------|
| <input type="checkbox"/> walking                     | <input type="checkbox"/> moving |
| <input type="checkbox"/> eating                      | <input type="checkbox"/> other  |
| <input type="checkbox"/> time of day (specify) _____ |                                 |

7. What makes the pain better?

- |  |  |
|--|--|
| <input type="checkbox"/> hot/cold  | <input type="checkbox"/> distraction       |
| <input type="checkbox"/> massage   | <input type="checkbox"/> lying still       |
| <input type="checkbox"/> relaxation  | <input type="checkbox"/> changing position |
| <input type="checkbox"/> medication  |  |
| <input type="checkbox"/> complementary therapies (therapeutic, healing touch, massage, etc.) |  |
| <input type="checkbox"/> other _____   |  |

revised – June 8, 2001

8. Does the pain interfere with:

- |  |                                     |
|--|-------------------------------------|
| <input type="checkbox"/> social activities   | <input type="checkbox"/> sleep/rest |
| <input type="checkbox"/> coping  | <input type="checkbox"/> talking    |
| <input type="checkbox"/> sexuality   | <input type="checkbox"/> appetite   |
| <input type="checkbox"/> performing Activities of Daily Living (bathing, shopping) | <input type="checkbox"/> emotions   |

9. Which pain medications/treatments have been tried in the past? Was it effective or ineffective?

10. What pain medications/treatments are presently being used (prescription or non-prescription)? Are they effective or ineffective?

11. What side effects are being experienced?

- |   |  |
|---|--|
| <input type="checkbox"/> nausea/vomiting    | <input type="checkbox"/> constipation      |
| <input type="checkbox"/> confusion          | <input type="checkbox"/> drowsiness        |
| <input type="checkbox"/> dizziness          | <input type="checkbox"/> diarrhea          |
| <input type="checkbox"/> anxiety            | <input type="checkbox"/> mood swings       |
| <input type="checkbox"/> restlessness       | <input type="checkbox"/> dry/sore mouth    |
| <input type="checkbox"/> decreased appetite | <input type="checkbox"/> urinary retention |
| <input type="checkbox"/> itchiness          | <input type="checkbox"/> weakness          |
| <input type="checkbox"/> depression         |  |

12. What has been prescribed for side effects?

- |   |
|---|
| <input type="checkbox"/> constipation/diarrhea _____              |
| <input type="checkbox"/> nausea _____                             |
| <input type="checkbox"/> anxiety _____                            |
| <input type="checkbox"/> appetite _____                           |
| <input type="checkbox"/> confusion/restlessness/mood swings _____ |

13. What are the goals/plan regarding pain control?

Allergies –

Date completed –





## The Dying Person's Bill of Rights



I have the right



- ...to be treated as a living human being until I die.
- ...to maintain a sense of hopefulness, however changing its focus may be.
- ...to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- ...to express my feelings and emotions about my approaching death in my own way.
- ...to participate in decisions concerning my care.
- ...to expect continuing medical and nursing attention even though "cure" goals have been changed to "comfort" goals.
- ...not to die alone.
- ...to be free from pain.
- ...to have my questions answered honestly.
- ...not to be deceived.
- ...to have help from and for my family in accepting my death.
- ...to die in peace and dignity.
- ...to retain my individuality and not be judged for my decisions which may be contrary to the beliefs of others.
- ...to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
- ...to expect that the sanctity of the human body will be respected after death.
- ...to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Created at a workshop on "Terminally Ill Patient and the Helping Person" in Lansing, MI. The workshop was sponsored by the Southwest Michigan Inservice Education Council and conducted by Amelia J. Barbus, Associate Professor of Nursing at Wayne State University.



# You matter because you are you

*Cicely Saunders*

