



Hospice and End-of-Life Care for Hmong Patients and Families

**February 25, 2008
Hospice Minnesota**

*Hla dej yuav hle khau.
Tsiw teb tsaws chaw yuav hle hau.*

- White Hmong proverb *

*When crossing a river, remove your sandals.
When crossing a border, remove your crown.*

**Source: “Healing by Heart: Clinical and Ethical Case Stories
of Hmong Families and Western Providers”; 2003**

MYTHS AND REALITIES OF HOSPICE CARE ¹

1. “Choosing hospice means I am giving up hope.”

When cure is no longer possible, hospice provides the type of care most people say they want at the end-of-life: comfort and quality of life. The most common statement made by families who choose hospice for their loved ones is, “*We wish we had known about hospice sooner.*”

2. “Hospice care will not allow me or my family to be involved in making treatment decisions.”

Hospice puts patients and families at the center of care. Trained hospice professionals provide guidance and encourage an open and honest communication about individual wishes and choices.

3. “My loved one died in a great deal of pain, but that’s just to be expected as part of the dying process.”

Hospice physicians, nurses, and other hospice professionals are specifically trained to manage each patient’s pain. The intent is to keep the patient as awake and alert as possible.

4. “I want to care for my loved one at home; I don’t want her/him to go to a hospice.”

Hospice is not a place; it is a philosophy of care. The majority of hospice care takes place in the home, where each patient can be surrounded by family and familiar settings.

5. “My loved one lives in a nursing home. I cannot care for her/him in my home, so hospice would not be an option.”

Hospice and palliative care is provided in nursing homes, assisted living residences, and even hospitals. Hospice care can occur wherever the patient lives or considers their home.

6. “Hospice care keeps people with a limited life expectancy heavily medicated. Hospice care focuses primarily on the physical process of dying.”

Hospice pain management is highly specialized and tailored to each individual. Pain management is provided so that each person can live every day to the fullest, experiencing the highest quality of life possible. Hospice care provides respectful emotional and spiritual support for each patient and family, including family bereavement support following the death of a loved one. Complementary music, massage, and pet therapies are often available.

7. “My loved one’s doctor suggested hospice; that must mean my loved one has only a few days left to live.”

Hospice care is available to anyone who has a life-limiting or terminal illness, with a prognosis of six months or less if the illness runs its normal course. Patients can remain in hospice longer than six months, if needed.

8. **“My loved one is dying from end-stage cardiac disease. I want the most compassionate care possible for her, but someone told me hospice care is only for older people with cancer.”**

Hospice programs can care for anyone, at any age, facing a life-limiting or terminal illness. Specific hospice care guidelines describe conditions of participation.

9. **“My loved one does not have private insurance, so she/he will not be able to afford good end-of-life care when it is needed.”**

Hospice is fully covered by Medicare, Medicaid, the Veteran’s Administration, and most HMOs and private insurance companies.

10. **“We live in a rural area, so there are no hospice programs to help me care for my daughter.”**

There are more than 4,100 hospice care organizations in the United States, making it possible to serve most regions. Less than one percent of Medicare beneficiaries live in an area where hospice care is not available.

11. **“You must be a DNR/DNI (Do Not Resuscitate/Do Not Intubate) to be in a hospice program.”**

It is not required that an individual prefers DNR/DNI for hospice care. Hospice programs cannot discriminate based on an Advance Directive preference.

12. **“You cannot have any type of treatment when you are receiving hospice care.”**

You can be treated for conditions not related to the terminal diagnosis. Hospice care aggressively treats the patient’s pain and other symptoms.

13. **“You must be home-bound to receive hospice services.”**

An individual receiving hospice care does not need to stay at home to receive services. If the patient is able, s/he can go out of the house for visits, medical appointments, and even on trips.

¹ Source: National Hospice and Palliative Care Organization. *For additional information, see www.nhpco.org.*

**Qhov kev neeg lam xav thiab qhov kev muaj tseeb ntawm
kev pab rau ib tug neeg thaum lub sij hawm pheej hmoo
los txog (los yog yuav tag sim neej)
*Myths & Realities of Hospice Care***

- 1. “Thaum kuv tab tom xaiv kev pab rau kuv lub sij hawm pheej hmoo los txog (hospice) txhais tau tias kuv tau tas kev cia siab lawm.”**

Yog txog thaum tias kuv tus mob yuav tsis tso kuv tseg lawm. Hospice yuav tu thiab pab tus neeg mob no kom zoo siab ua ntej nws yuav tso lub ntiaj teb no tseg. Txawm tias lub sij hawm tsawg tsawg lawm xwb los, yuav pab txhawb tus mob lub siab, thiab pab kom nws tau siv nws lub sij hawm tseem ceeb thiab muaj nqis rau nws lub neej. Ntau zaus, peb tau hnov tsev neeg los yog tus neeg mob uas tau kev pab los ntawm hospice lawv cov lus hais tias: “Peb xav kom peb paub txoj kev pab hospice no ntxov dua nod.”

- 2. “Hospice tsis pub kuv los yog kuv tsev neeg tawm tswv yim txog kev pab kho rau kuv.”**

Hospice yeej saib tus neeg mob thiab nws tsev neeg rau qhov chaw sam xeeb thiab rau nqi, vim nws tsev neeg yog qhov chaw txhawb nqa ntawm peb txoj kev kho mob no ntag. Peb cov ua hauj lwm uas tau kawm tawm txog kev pab no, lawv yuav txawj pab nej kev txhawb siab, ua siab dawb paug pab kom tau raws li tus mob thiab nws tsev neeg txoj kev ntshaw thiab txoj kev xaiv.

- 3. “Lub sij hawm tus yus hlub mob hnyav es yuav tag sim neej mas yog ib qhov nyuab heev, tab sis qhov no kom txhob tu siab thiab txob ntshai thaum ib tus neeg yuav tuag ces yeej yuav hlav tsis dhau txoj kev niaj mob li hais no.”**

Hospice cov kws kho mob, cov kws tu mob (nurse) thiab nrog nws pawg neeg ua hauj lwm yuav tuaj pab muab tshuaj txo nws tus mob kom mloog taus. Lub hom phiaj yog pab kom nws txhob hnov mob es tham tau nrog nws tsev neeg lub sij hawm yuav tso sawv daws tseg uas zaum kawg.

- 4. “Kuv xav tu tus neeg kuv hlub rau tom vaj tom tsev thiab kuv tsis xav kom nws mus rau tom hospice.”**

Hospice tsis yog ib qho chaw tu neeg mob. Nws yog ib lub tswv yim tu neeg mob thaum lub sij hawm pheej hmoo los txog. Qhov tseeb, hospice yog txoj kev tu neeg mob nyob rau tom tsev es thaum nws yuav puv 120 xyoo, nws tsev neeg thiaj pom thiab uas chaw sov siab rau nws thaum yuav ncaim mus.

5. “Tus neeg kuv hlub no nyob rau tom tsev laus kuv thiab hospice yuav mus pab tsis tau nws.”

Kev pab ntawm hospice, los yog “palliative care” yuav kam mus pab rau tom tsev laus, tom tsev tseem hwm pab-assisted living, los yog tom tsev kho mob loj. Kev pab kho mob hospice kuj kam mus pab nyob txhuav qhov chaw uas yog tu neeg mob nyob, los yog qhov chaw nws zoo siab tso nws txoj sia.

6. “Hospice txoj hauj lwm tseem ceeb yog muab tshuaj pab kom tus neeg mob txhob hnov mob qhov twg thaum tseem muaj txoj sia me me nyob. Hospice pab tus neeg mob ntawm cev nqaij daim tawv kom txhob mob heev ua ntej nws txoj sia yuav tu.”

Kev pab ntawm hospice yog pab tshuaj ntsuam ib tug neeg twg qhov mob thiab muab tshuaj kom haum rau tus neeg ntawd qhov mob kom txog thaum nws tag sim neej. Tsis tag li ntawd, hospice pab sam fwm dej siab dej ntsws thiab txhawb dag zog rau nws tsev neeg thiab pab kom tsev neeg ua siab loj tuaj tom qab thaum nws tau tso lawv tseg. Hospice kuj pab tso nkauj, tso kwv txhiaj txias txias nrog qhov maj mam zuaj pab kom nws tuag txhob hnov mob kiag li.

7. “Tus neeg kuv hlub no, Dr. xav kom muab kev hospice pab rau nws, qhov no yeej yog qhia tias nws muaj sij lawm luv luv nyob lawm xwb.”

Hospice kam muab kev pab rau txhua tus neeg muaj mob hnyav thiab yuav tag sim neej sai sai lawm – sij hawm 6 hli los yog tsawg tshaj. Muaj tej zaum, tej tus neeg mob kuj yuav nyob rau hospice pab ntau dua 6 lub hlis kuj muaj thiab.

8. “Tus neeg kuv hlub no muaj mob plawv tej zaum yuav kho tsis tau lawm. Vim li kuv xav tau kev pab hospice kom zoo rau nws. Tab sis muaj neeg hais rau kuv tias kev pab hospice no yog rau cov neeg laus thiab mob 'cancer' xwb.”

Kev pab ntawm hospice no yog pab rau txhua leej txhua tus, tsis hais tus laus tus hluas. Tsis hais tus muaj mob hom twg, los yog tus muaj mob kho tsis tau lawm. Kev pab ntawm hospice yog yuav pab tus neeg mob kom nws to taub txog nws tus mob zoo thiab qhia nws txog ntawm txoj kev pab raws li qhov nws nyiam.

9. “Kuv tus neeg mob tsis muaj ntawv kho mob zoo, vim li kuv ntshai tsam nws tsis tau txais kev kho mob zoo thaum nws yuav tag sim neej.”

Tsis hais cov ntawv kho mob hom twg los hospice yeej txais tib si, xws li: HMO, Medicaid, Medicare, los yog yus siv yus li nyiaj txiag los them kuj tau.

10. “Wb nyob deb nroog heev, ntshai hospice yuav tsis muaj kev pab pub rau wb tus nxhais.”

Hospice muaj ntau tshaj li ntawm 4,100 qhov chaw uas nyob thoob plaws America teb no kom los pab tau cov neeg mob txhua cheeb tsam lawv nyob. Ib feem puas (1%) ntawm cov neeg muaj cov ntawv kho mob Medicare yeej nyob nrog deb uas peb kev pab tseem mus tsis tau txog.

- 11. “Koj yuav tau kev pab ntawm hospice, koj yuav tsum muaj daim ntawv kos npe hais tias koj yeej tsis pub neeg cawm koj lawm, DNR/DNI (Do Not Resuscitate/Do Not Intubate).”**

Koj txawm tsis muaj daim ntawv tso cai no los koj yeej yuav tau txais kev pab. Hospice yuav tsis muaj qhov hais tias tsis kam pab kho koj vim koj tsis muaj daim ntawv li hais no.

- 12. “Yog koj tau txais kev pab ntawm hospice lawm ces koj yuav tsis tau txais lwm yam kev pab.”**

Txhua yam mob ntsia ntsees rau koj txoj sia lub sij hawm nyob hospice los lawv yeej yuav pab tib si. Hospice yuav muab tshuaj kho kom koj tus mob ntaug, tsis pub koj niaj mob.

- 13. “Lub sij hawm koj nyob rau hospice, koj yuav tawm mus qhov twg yeej tsis tau.”**

Tsis yog cov neeg tau txais kev pab hospice no yuav tawm mus los qhov twg tsis tau. Yog tus neeg mob no nws tseem taus, nws yeej mus tawm sab nraud tau, xws li mus xyuas tej txheeb ze, mus cuag kws kho mob, los yog mus yos ua si kom zoo siab los tau tsuav nws tseem muaj peev xwm.

The Hospice Philosophy

“Hospice is a concept or a philosophy of care.

It is not a building or a place, but a way of helping people - individuals, families and communities - live until they die.

That helping process is a mixture of community, social, spiritual, bereavement and traditional health and medical services.”

- Elisabeth Kübler-Ross

Hospice Care *

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Holistic care which integrates the psychological and spiritual aspects of patient care
- Enables the patient to live as actively as possible until death
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement

Criteria for Hospice Admission

- A limited life expectancy, usually six (6) months or less, as certified by a physician
- The understanding that hospice care is palliative (comfort care) - focused on pain and symptom control rather than a cure for the disease

* Source: World Health Organization, 1990



Local Medical Review Policies (LMRPs)

- Every disease category has criteria for hospice
- General criteria
- Specific criteria



What do these terms mean?

- Hospice Benefit Periods
- Discharge
- Recertification
- Revocation



Hospice Care and Services

- Physician services
- Nursing services on an intermittent basis
- Home health aide and homemaker services
- Medical social services
- Spiritual care and counseling
- Trained volunteers
- Alternative therapies
 - Music therapy
 - Pet therapy
 - Massage therapy
- Medications – pain and symptom control
- Physical, occupational, speech therapy
- Medical supplies and equipment
- Respite care
- Continuous care at home during a crisis
- Short term inpatient care
- Bereavement services

IS HOSPICE THE ANSWER?

Watch for these signs and symptoms.²

Has the individual you are caring for

- Been to the hospital Emergency Room (ER) several times in the past few months?
- Seen their physician more often than usual?
- Complained or shown evidence of pain on a daily or almost daily basis?
- Increased their use of pain medications?
- Fallen several times over the past six months?
- Started feeling weaker and more tired, even though they may be sleeping more?
- Had any of the following health conditions?
 - Recurring fever
 - Recurring infections (UTI, URI)
 - Increasing shortness of breath, (even when resting)
 - Internal bleeding
 - Pressure ulcers which do not heal
- Had a significant decline in functional status/ADLs over the past six (6) months?
 - Bathing
 - Dressing
 - Getting out of bed
 - Walking
 - Eating
 - Toileting
- Had their MDS (SNF residents) trigger several Quality Indicators?
- Received chemotherapy or radiation for cancer treatment and it no longer benefits them?
- Received dialysis for kidney disease and it no longer benefits them?
- Had a weight loss of ten percent (10%) of their body weight over a six (6) month period of time (not trying to lose weight)?
- Been diagnosed with a life limiting condition?

Is there an Advance Directive preference for several of the following items:

- Do not resuscitate/Do not intubate
- Do not initiate tube feedings
- Do not hospitalize
- No antibiotics
- No blood transfusions
- No IV hydration
- No lab/x-rays
- Comfort care only

Do you talk about futility when you discuss advance directives?

- If the cure is worse than the disease, consider hospice.
- When your client says “I am dying...”

² Source: National Hospice and Palliative Care Organization and Hospice of the Twin Cities, 2007

WHO PAYS FOR HOSPICE?

- Medicare (Part A)
 - The federal all-inclusive hospice care benefit
- Medical Assistance
 - 43 States have a MA hospice benefit
- Commercial Insurance Carriers
- Health Maintenance Organizations (HMOs)
- Veterans Hospice Benefit
- Private Pay
- Indigent Care
 - Hospice will help families find out if the patient is eligible for any coverage they may not be aware of. Many hospices may provide care for someone who cannot pay, using money raised from the community or from memorial or foundation gifts.

Qhov Muaj Tseeb? *Who pays for hospice?*

Tsis yog tias laus lawm ces yuav tsum niaj mob. Txhob niaj mob yuav tsum mus cuag kws kho mob kom tshuaj ntsuam xyuas thiab muab tshuaj pab kho kom zoo xws li lwm cov neeg mob thiab.

Tsis yog ib qho uas yuav cia li lam xav hais tias tus laus mob ntawd kus kes xwb es pheej yuav pab nws dab tsi, los yog muab tshuaj tsis txaus rau nws qhov mob.

Ntau tus laus yog mob heev lawm, lawv yuav tsis kam qhia txog lawv kev niaj mob. Vim lawv ntshai tsam yuav tau noj tshuaj, raug tshuaj ntsuam tus mob ces dhuav lawv heev. Cov xav li no mas, lawv yuav tsis kam hais txog lawv qhov mob li .

Ntau tus laus yuav tsis kam qhia lawv txoj kev niaj mob. Vim lawv qhov mob no mob tshaj qhov yuav qhia tau lawm.

Ntau tus neeg muaj kev niaj mob sib txawv. Ntau zaus txoj kev niaj mob no mob loj tshaj qhov neeg hais tau tawm, ces cia li ua rau lawv nkees heev thiab xav tsaug zog tas mus li xwb los yog ua kom lawv qaug txaj kiag.

Cov tshuaj muaj yeeb no ntxim heev rau kev kho neeg muaj mob ntsaj li hais no, los yog mob dhau lawm ua rau lawv nkees thiab mob ib ce ntsoog tag.

Cov laus yuav qaug tshuaj heev. Qhov no tsis tau qhia hais tias yuav tsum txhob muab tshuaj muaj yeeb pab lawv tus mob ntxiv lawm. Qhov zoo yuav tsum yog ntsuam xyuas kom zoo es muab tshuaj kom haum rau lawv tus mob thiaj pab tau lawv zoo.

WHAT IS PAIN? HOW IS IT MEASURED?

“Pain is whatever the person experiencing it says it is, and existing whenever s/he says it does.”

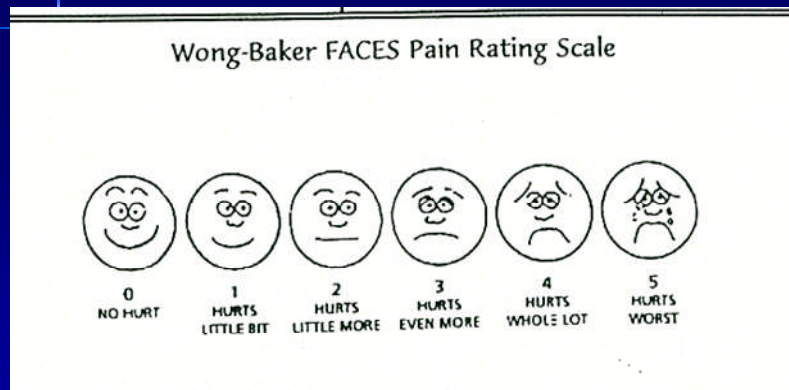
- Margo McCaffery, RN, MS, FAAN

1. Vertical Pain Scale

	10
	9
	8
	7
	6
	5
	4
	3
	2
	1
	0

2. Wong-Baker Faces Pain Scale

Pain Assessment Scale



Kev mob ntsaj yog dab tsi? What is pain? How is it measured?

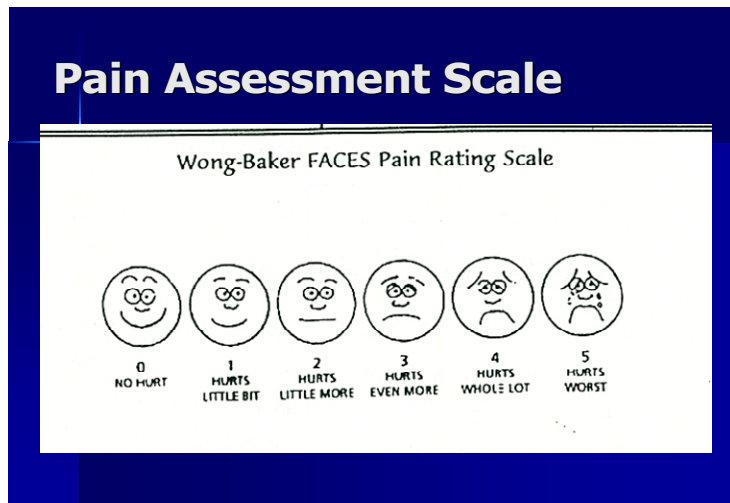
Kev mob ntsaj txhais tau tias thaum ib tug neeg tsa ncauj tias nws mob, mob heev lawm, los yog nws nroo/ntsaj tawm ces qhia tau tias nws yeej mob lawm tiag.

1. Margo McCaffrey siv kev tshuaj ntsuam 0 -10 los ntsuas kev mob ntsaj.

1. Vertical Pain Scale

10	Mob heev tshaj li/uv tsis tau lawm.
9	Mob heev
8	Mob heev
7	Mob mloog tsis tau lawm
6	Mob mloog tsis tau lawm
5	Mob mloog tau
4	Mob mloog tau
3	Mob me ntsis
2	Mob me ntsis
1	Tsis mob
0	Tsis mob

2. Wong-Baker siv 6 lub ntsej muag li nram no los ntsuas kev mob ntsaj.



0: tsis mob

1: mob me ntsis

2: mob mloog tau

3: mob mloog tsis tau lawm
lawm xwb

4: mob heev

5: mob heev tshaj li/quaj yuav

FACTS ABOUT PAIN FOR ELDERS & OLDER ADULTS

- 80% of elders have a chronic complaint associated with pain.
- Elders may be less sensitive to the cutaneous (skin) sensation of certain kinds of stimuli (i.e. heat and cold).
- Many elders tend to under-report their pain experience. Some may actually deny pain for fear of prolonging hospital stays. Under-reporting and denial do not mean s/he does not experience pain.
- The three (3) most reported areas of pain are:
 - Painful joints (hip/back)
 - Head
 - Chest
- Pain becomes something to tell others about when it interferes with sleep, movement, social, and leisure time. Some individuals may report that it limits their activities of daily living.
- Individuals with chronic pain (low back, neck, arthritis) tend to be depressed.
- The most frequent conditions which cause pain are arthritis, cardiovascular disease, falls, trigeminal neuralgia, osteoporosis, cancer, and herpetic neuralgia (shingles).

MYTHS AND FACTS ABOUT PAIN FOR ELDERS/OLDER ADULTS

MYTHS	FACTS
Pain is expected with aging.	Pain is not normal with aging. Pain must be assessed, diagnosed, and managed for elders, as well as all other patients.
Pain sensitivity and perception decrease with age.	This is a dangerous assumption with consequences of needless suffering and under-treatment of pain and the underlying cause.
If a patient does not complain of pain, s/he must not experience it.	Patients may not report pain for a variety of reasons. They may fear the meaning of pain, diagnostic workups, or pain treatments. They may see pain as normal or not want to be seen as complainers.
A person who shows no signs or symptoms of pain, or is distracted from pain, must not have significant pain.	Patients have a variety of reactions to pain. Many patients are stoic and refuse to “give in” to their pain.
A person who sleeps must not have much pain.	Pain results in severe fatigue. Many patients become exhausted by pain, resulting in extended sleep.
Opioid medications are inappropriate for patients with chronic non-malignant pain (arthritis, chronic back pain, etc.).	Opioid medications are appropriate for patients with many kinds of pain.
Potential side effects of opioid medications make them dangerous to use with elder persons.	Opioids may be used safely, although some elders may be more sensitive to them. This does not justify withholding opioids and failing to treat pain.

**Kev lam tau lam xav thiab qhov muaj tseeb ntawm kev pab cov
laus txoj kev niaj mob nstaj thaum yuav tag sim neej**
Myths and Facts About Pain

Qhov Neeg lam xav

Laus lawm ces yeej yuav tsum muaj mob muaj nkeeg thiab niaj mob.

Laus lawm yeej yuav mob ub, mob no zoo li no.

Tsis yog tus neeg mob tsis nroo txog ces yog nws tsis mob, los yog yeej tsis mob heev

Tsis yog thaum ib tug neeg nws ua li tsis hnov qhov mob, los yog nws qhia tsis tau tias nws mob ces yog nws yeej tsis mob.

Tus neeg pw tsaug zog heev yuav tsum yog tus neeg tsis hnov mob.

Tej tshuaj muaj yeeb yuav tsis tsim nyog koj los siv rau cov neeg tsis mob khees xawj (CA), los yog lwm yam mob los ntev, thiab kho tsis zoo xws li: mob yas tes yas taw, mob duav thiab mob thoob ib ce ect...

Qhov tsis zoo ntawm cov tshuaj muaj yeeb no yog tsam ua tsis zoo rau cov laus.

Qhov Muaj Tseeb.

Tsis yog tias laus lawm ces yuav tsum niaj mob. Txhob niaj mob yuav tsum mus cuag kws kho mob kom tshuaj ntsuam xyuas thiab muab tshuaj pab kho kom zoo xws li lwm cov neeg mob thiab.

Tsis yog ib qho uas yuav cia li lam xav hais tias tus laus mob ntawd kus kes xwb es pheej yuav pab nws dab tsi, los yog muab tshuaj tsis txaus rau nws qhov mob.

Ntau tus laus yog mob heev lawm, lawv yuav tsis kam qhia txog lawv kev niaj mob. Vim lawv ntshai tsam yuav tau noj tshuaj, raug tshuaj ntsuam tus mob ces dhuav lawv heev. Cov xav li no mas, lawv yuav tsis kam hais txog lawv qhov mob li .

Ntau tus laus yuav tsis kam qhia lawv txoj kev niaj mob. Vim lawv qhov mob no mob tshaj qhov yuav qhia tau lawm.

Ntau tus neeg muaj kev niaj mob sib txawv. Ntau zaus txoj kev niaj mob no mob loj tshaj qhov neeg hais tau tawm, ces cia li ua rau lawv nkees heev thiab xav tsaug zog tas mus li xwb los yog ua kom lawv qaug txaj kiag.

Cov tshuaj muaj yeeb no ntxim heev rau kev kho neeg muaj mob ntsaj li hais no, los yog mob dhau lawm ua rau lawv nkees thiab mob ib ce ntsoog tag.

Cov laus yuav qaug tshuaj heev. Qhov no tsis tau qhia hais tias yuav tsum txhob muab tshuaj muaj yeeb pab lawv tus mob ntxiv lawm. Qhov zoo yuav tsum yog ntsuam xyuas kom zoo es muab tshuaj kom haum rau lawv tus mob thiaj pab tau lawv zoo.



Ua tsaug

Hospice
MINNESOTA
for care of the dying