



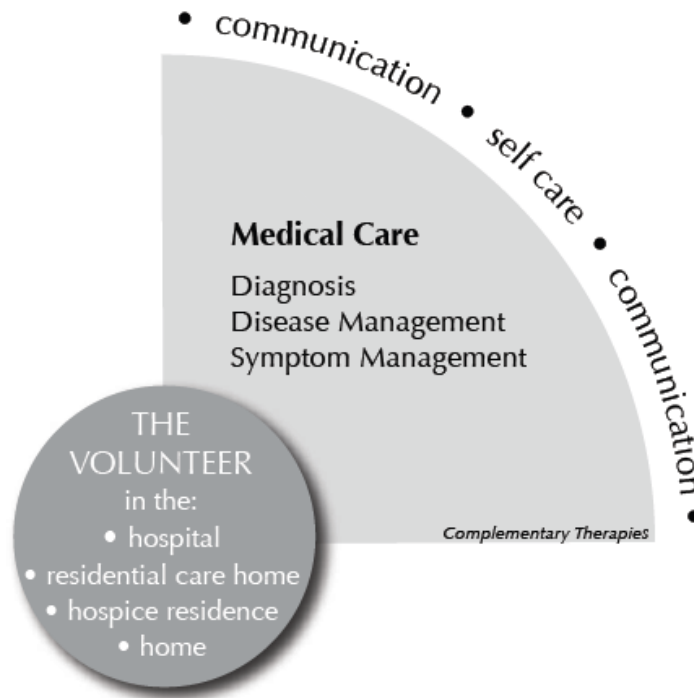
Module 2

MEDICAL CARE

*At the end of life
when restoring health is no longer possible
Healing becomes more
than just the relief
of pain, suffering, and emotional distress.
During this challenging time
Healing manifests on the purest level--
an extension of the soul
a reflection of the spirit.*

*Real Healing is
an authentic expression of caring and love,
an aide in accepting a life drawing near,
helping a person discover a calming peace
and a place of serenity on the journey leading to transition.*

Kirsti A. Dyer MD, MS. from *Healing: A Gift of Self*



Learning Outcomes

Upon completion of the Medical Care module, volunteers will:

1. Have a general understanding of the medical care component.
2. Understand and respect the limits of their role in relation to medical care.
3. Have the competence and capacity to carry out their responsibilities.
4. Be familiar with community resources and systems of service delivery.

Definition of Medical Care

Medical care is the primary responsibility of professional members of the hospice palliative care team – those who assess, diagnose and manage the client's disease (doctors, nurses, technicians, pharmacists, etc.). Symptom management and pain control are also the responsibility of the medical team. It is helpful for volunteers to be familiar with the composition and roles of the medical team for their own sake and for the benefit of the clients they serve.



Medical Care and The Role of Hospice Volunteer in Different Settings

Setting	Medical Care	Volunteer Role
Hospital	<ul style="list-style-type: none"> • More medical treatments are available on site. 	<p>In all settings the volunteers will have no responsibilities for medical care of their clients. Their role may be to:</p> <ul style="list-style-type: none"> • Be supportive and respectful of the medical team. • Be familiar with the policies and procedures in each setting that relate to volunteers. • Know when to call for assistance. • Record observations that may assist professional staff (and volunteers) coming on duty *(communication book). • Be prepared to listen while the client talks about her condition without offering medical information or advice. • Be able to direct the client’s/family’s questions to the right person. • **Hand the client a medication that has been prepared by the family member or nurse, (usually only when a family member is not available). • ** Assist in the moving or turning of a client in the home setting.
Hospice Residence	<ul style="list-style-type: none"> • Primarily nursing care with visits from doctors. • Pain and symptom management. 	
Residential Care Home	<ul style="list-style-type: none"> • Primarily nursing care with visits from doctors. • Pain and symptom management. 	
Home	<ul style="list-style-type: none"> • Home care nurse will administer medication, change dressings, communicate to medical staff on behalf of client. • Home support workers or community service workers may provide some medical care, under supervision. • Doctor may visit occasionally. 	

* Many hospice societies and/or health authorities have developed a “communication book” to support clients and their families on their journey. In binder format, it may provide sections for: recording the names and contact information of the client’s support team, including the volunteer; an appointment calendar; a chart for recording medication details; information and helpful advice; and a daily journal for recording questions, events, thoughts, feelings and messages to and from family, friends and support team members.

** As regulations related to medication assistance and lifting and moving a client will vary from region to region and setting to setting, hospice organizations must ensure volunteers are informed and respect the regulations relating to their work setting. These regulations may change over time and volunteers must be kept informed.



Training

Orientation and Basic Training

1. Provide a general overview of what medical care involves. Include information on how medical care is managed in each of the settings in which your volunteers will be working.
2. Provide a tour of each setting in which the volunteer will be working and introduce volunteers to medical members of the hospice palliative care team, if possible.
3. Promote an environment of collegiality where volunteers feel comfortable asking questions.
4. Introduce volunteers to new staff who may be working during the volunteers' shifts.
5. Ensure that volunteers understand and respect the policies and regulations in each setting they will be working, around feeding and moving/turning a client.
6. As regulations vary significantly from region to region and setting to setting, new volunteers who have worked in other regions must be oriented to their new situation.
7. Incorporate a mentoring or "job shadowing" component to allow volunteers to learn on the job from an experienced volunteer.
8. Review universal precautions, including proper handwashing procedures.
9. Provide an orientation to the Palliative Performance Scale (PPSv2). See "Resources".

Ongoing Training

1. If and when appropriate, provide opportunities for volunteers to sit in on medical components of hospice palliative care team meetings, information and debriefing sessions, etc.
2. In keeping with your organization's policies, provide opportunities for volunteers to participate in training sessions on specific procedures if you think the knowledge will enhance the volunteers' abilities to support their clients – whether or not they are permitted to carry out the procedure (i.e. feeding, moving, etc.).
3. Include a segment on emergency preparedness.
4. Provide facts about pain management including the use of non-medical approaches.
5. Include a segment on non-cancer illnesses.

RESOURCES

Module 2 MEDICAL CARE

RESOURCES

- ❖ **About Pain**
- ❖ **Pain Management**
- ❖ **Palliative Performance Scale from Victoria Hospice**
- ❖ **Physical Process of Dying: Adapted from Victoria Hospice**
- ❖ **The Dying Process ~ Final Hours**

ABOUT PAIN

What is Pain?

Pain: “An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.” (*International Association for the Study of Pain*).

Pain: “Whatever the person experiencing it says it is, existing whenever he says it does.” (McCaffery, 1999) “The mainstay of pain assessment is the patient’s self-report” (Jacox, Carr, Payne et al, 1994, p.3).

Pain is a major symptom in those who are terminally ill.

Terms people use to describe their pain:

Hurt – Ache – Uncomfortable – Tingling – Burning – Shooting – Cramping – Pins and needles – Dull – Sharp – Stabbing

The experience and expression of pain is determined by personal and cultural values, gender, and age.

- ❖ Stoicism vs. verbal and emotional expression: Some cultures value silent suffering, while others expect intense verbal and emotional response to pain.
- ❖ Women tend to be more communicative about their experience of pain than men
- ❖ Older persons may have grown up with the idea that pain is something to be expected as one ages, or with the belief that pain is something shameful or not to be “complained” about (“Mind over Matter”)

The presence of pain is not necessarily demonstrated in the sufferer’s behaviour. A person may report severe pain, yet have a calm facial appearance, may be talking and laughing with friends, or may be asleep (and only reports the pain on awakening). We should never disbelieve a person’s report of pain, or a family member’s insistence that the person is in pain, when the person cannot self-report.

Many people report less pain than they are actually having. There are several reasons for this. Often people fear that an increase in pain means the disease is worsening, or that feeling pain is to be expected when one has an illness and must be tolerated. Some people believe that pain is either punishment for past sins or a way to attain salvation in the after life. Fear of addiction to pain medication or fear that using a strong painkiller now will prevent good pain relief in the future when the pain gets worse may result in people not reporting the pain they are experiencing.

Every patient should be encouraged to speak openly and honestly to the nurse and the doctor about the physical pain they are having, and to take their pain medicines as prescribed. Poorly controlled pain and uncontrolled pain increase suffering and diminish quality of life. At the same time it is important to respect the person’s right to choose to not report pain or not take pain medication. For some people, physical suffering is meaningful. The important thing is to ensure that patients and families know the facts about pain and pain management, in order that they can make informed decisions.

Courtesy Mission Hospital Society
RESOURCES: BCHPCA FACILITATOR’S GUIDE

ABOUT PAIN cont'd

Cancer Pain

There are several different types of pain associated with cancer. Knowing what kind of pain a person is experiencing and where the pain is located helps the doctor determine how best to treat it, including the choice of pain medication. It is important to assess pain intensity and the level of distress it is causing the sufferer and whether the treatments are effective in relieving the pain.

Since pain is subjective it is necessary to ask the person experiencing it to describe the pain, and to rate its intensity using some kind of scale. There are ways to assess pain in people who are unable to communicate, but usually these scales are useful in only a general way and often their accurate interpretation depends on how well the observer knows the sufferer.

Acute Pain:

- ❖ starts suddenly and is usually relieved within days, but may last a few weeks
- ❖ may be related to surgery or radiation treatments; sometimes is the result of tumour growth (such as pain that occurs with bowel obstruction)
- ❖ usually is the result of tissue damage and inflammation is often present
- ❖ may or may not be obvious to an observer, and the patient may or may not appear anxious

Chronic Pain:

- ❖ pain that has been present for longer than 3 to 6 months, and that persists beyond the expected course of an illness or injury
- ❖ associated with a chronic disease process, such as arthritis or cancer
- ❖ may lead to depression
- ❖ often not obvious to an observer

***The longer pain persists, the more intense it becomes.

Nociceptive Pain: caused by tissue damage; can be acute or chronic.

Neuropathic Pain: caused by injury to nerves or to the central nervous system (following a stroke, for example); can be acute or chronic.

Mixed Pain: has both nociceptive and neuropathic features.

Total Pain

A person is made up of body, mind, and spirit and spends his or her whole life (usually) in relationship with other people. Therefore, when an illness such as cancer strikes, it affects more than just the individual and more than just the physical body. Cecily Saunders coined the term "Total Pain" to capture the all-encompassing nature of the pain experienced by those with a terminal illness.

Psychological, emotional, social, financial, and spiritual pain contribute to the experience of physical pain (See Total Pain graphic). Physical pain can be made worse when other sources of pain are not addressed. This is another reason that an interdisciplinary team is so important.

ABOUT PAIN cont'd

Pain Management

I. Use of Medications

It is important to understand the source of the pain in order to treat it effectively, but it is equally important to have some way of determining how severe the pain is and whether or not the treatment is effective in controlling the pain. The best way of doing this is to use a scale, such as 0 = No Pain ---□ 10 = Worst Pain Imaginable, and ask the person to say where on that scale they would rate their pain. Pain intensity should be assessed before and after giving the person some form of treatment for the pain. Sometimes a person is willing to have *some* pain, but the goal of comfort should be negotiated between the patient and the doctor or nurse.

Usually the comfort goals are:

1. First, to be comfortable during the night and to get a good sleep.
2. Next, to be comfortable during the day while at rest.
3. Finally, to be comfortable during the day when one is moving around and doing the things that are important to the person.

Mild, Moderate, and Severe Pain

The World Health Organization developed a simple model to guide health professionals in choosing the most appropriate pain medication for the severity of pain being experienced. (See WHO Analgesic Step Ladder) There are two basic types of pain medicine: non opioid (for mild pain) and opioid (for moderate and severe pain). Opioids are drugs such as codeine and morphine.

Mild Pain

- Acetaminophen (Tylenol)
- Anti-inflammatory drug, such as ibuprofen
- Tylenol #3 (codeine) or MOS (morphine syrup)

Moderate

- Codeine
- Morphine
- Hydromorphone (Dilaudid)
- Fentanyl patch

Moderately Severe and Severe Pain

- Morphine
- Hydromorphone (Dilaudid)
- Fentanyl patch
- Methadone*

*Methadone is a very effective drug for people with severe pain, especially when the pain is both from the cancer and from nerve injury. If a person is taking methadone it does NOT mean that he or she is a recovering addict.

ABOUT PAIN cont'd

Pain Management cont'd

Myths about Morphine (and other opioids)

1. MYTH: “You need to save strong pain medication for when the pain gets worse.”

- a. FACT: Treating pain early can prevent worse pain and loss of function.
- b. FACT: There is no limit to the amount of opioid that a person can take.

2. MYTH: “Taking strong pain medication will cause a person to become addicted.”

- a. FACT: Less than 0.1% of patients taking opioids for pain control become addicted.
- b. FACT: Addiction is a compulsive desire to take a drug such as morphine in order to experience the “high”. People with pain take the drug in order to relieve the pain.

Side Effects of Opioids

- 1. Constipation – This always accompanies the taking of opioids, and can be prevented or treated by the regular use of a laxative. Stool softeners alone are rarely effective in preventing constipation.
- 2. Nausea, with or without vomiting – This is commonly seen when people first start taking an opioid, and can be prevented or treated by several kinds of medication. Nausea can also be caused by constipation.
- 3. Drowsiness, decreased mental alertness – This side effect usually decreases or disappears within a few days, but will re-occur whenever the drug dose is increased; this is also a natural occurrence as people come closer to death.
- 4. Itchiness, especially an itchy nose.
- 5. Difficulty with urination – This sometimes occurs in elderly people who are taking opioids.
- 6. Respiratory depression – This is rarely a problem when a person has been taking an opioid for some time.

II. Other Ways of Managing Pain

- 1. Surgery
- 2. Radiation
- 3. Chemotherapy
- 4. Nerve blocks
- 5. Acupuncture
- 6. Massage, positioning
- 7. Heat/Cold

ABOUT PAIN cont'd

Other Ways of Managing Pain cont'd

Remembering the concept of Total Pain, there are a number of other important ways to control pain. Hospice volunteers are able to provide some or all of the following helpful interventions:

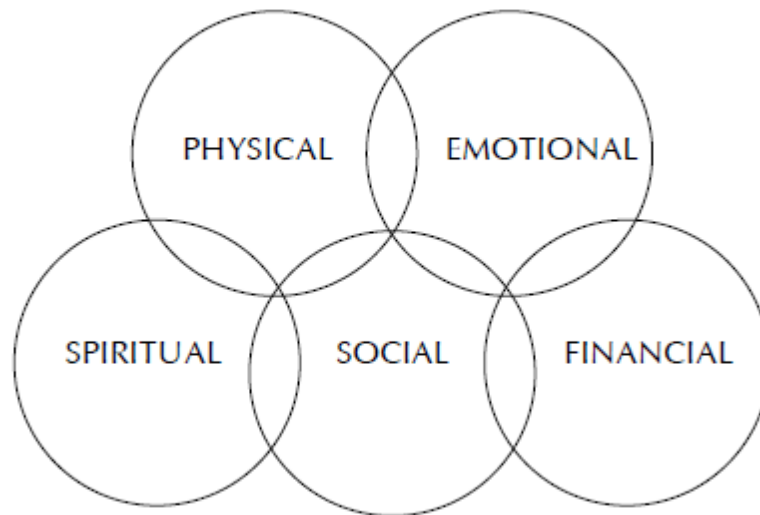
- Listening, companionship
- Use of Imagery
- Relaxation techniques
- Therapeutic touch, Healing touch
- Distraction (games, music, watching TV or movies, outings, arts and crafts, creation of a legacy)
- *If the person requests:* reading of scriptures, singing of hymns, prayer.

Counselling for the person and family members, assistance with putting affairs in order, and making final arrangements are other services that the interdisciplinary team can offer, and that will have an impact on Total Pain.

Total Pain Concept

The dying person's perception of and response to pain has emotional, social, spiritual and psychological components. All components are interrelated and can increase sensation of pain.

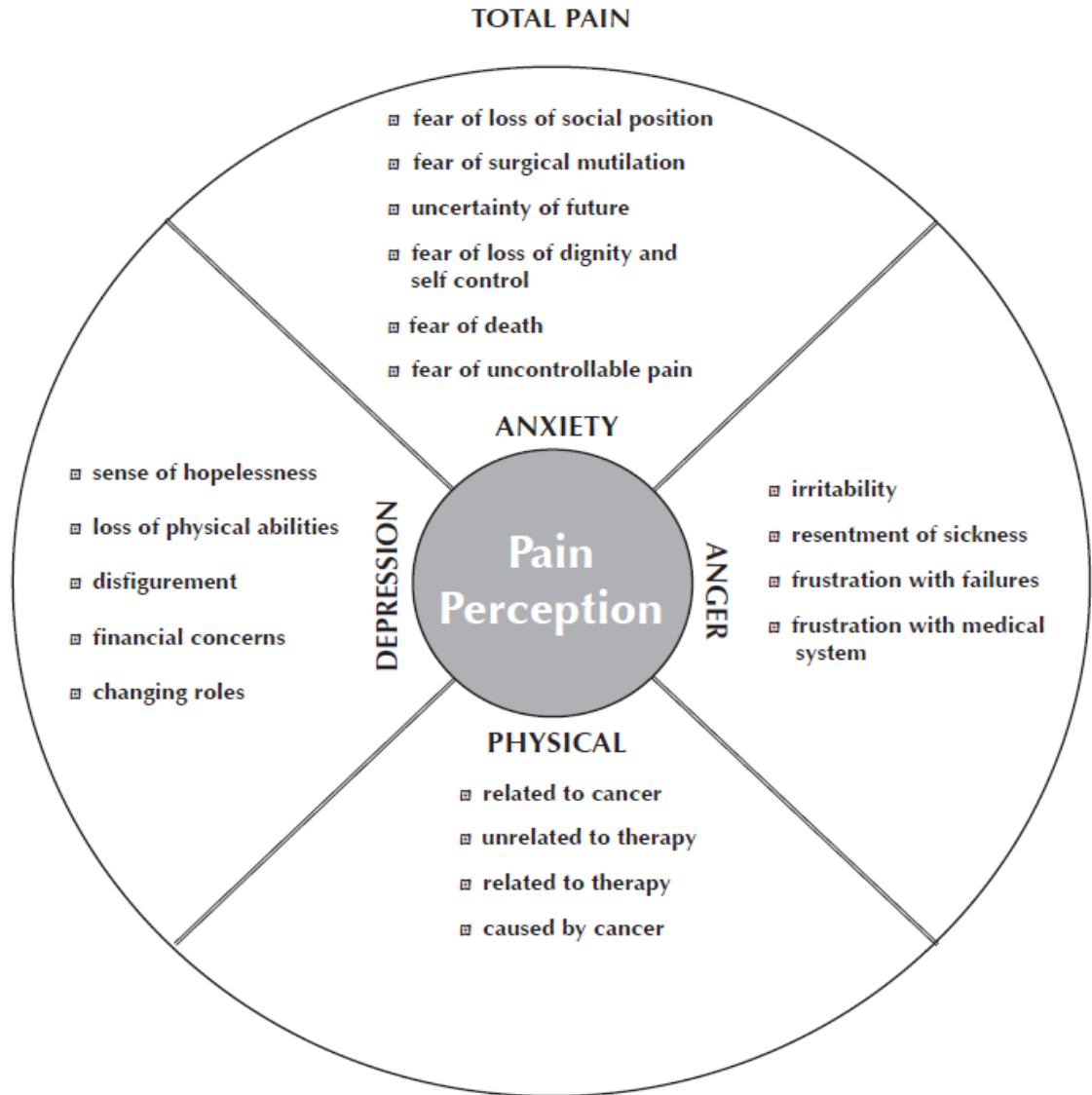
THE MULTIFACETED COMPONENTS OF PAIN



Source: Multifaceted Components of Pain, Amenta and Bohnet, 1986

Courtesy Mission Hospital Society
ESOURCES: BCHPCA FACILITATOR'S GUIDE

ABOUT PAIN cont'd



Courtesy Mission Hospital Society
RESOURCES: BCHPCA FACILITATOR'S GUIDE

PAIN MANAGEMENT

Physical pain cannot be treated in isolation from other causes of suffering - for example anxiety, grief, spiritual concerns. Addressing these issues together with pain management strategies reduces the need for strong analgesics.

Pain is what the person says it is; not what anyone else thinks it should be.

Pain can be controlled in most situations. Unless it is their choice, there is no excuse for anyone's attention to be focused on their discomfort.

The degree of pain does not relate to the extent of the illness. Some people with advanced disease may have no pain, while someone with the same tissue damage may experience severe pain.

In terminal illness, several different types of pain usually occur together and require different therapies simultaneously. For example: pain from invasion of a tumor into surrounding tissue, pain from swelling, hypersensitivity in the hands and feet from chemo and muscle aches from weakness and inactivity.

Pain Management Strategies

Encourage people to utilize the pain relief methods they believe in, regardless of whether you believe them to be helpful or not.

- Attention to issues beyond the physical pain (fear, stress, anxiety)
- Rest and relaxation (maybe through music, visualization, listening to stories etc)
- Application of heat or cold
- Imagery
- Alternative therapies (healing touch, massage, biofeedback, acupuncture, acupressure, crystals, herbal remedies, etc.)
- Analgesics
- Surgery

Analgesics:

- Over-the-counters such as Tylenol, Ibuprofen, ASA
- Combinations such as Tylenol or ASA with codeine – prescription
- Coanalgesics treat something other than pain but also alter the experience of pain.
- Narcotics or Opioids such as Morphine, Demerol, Diladid

Morphine

Side effects include constipation, sedation, nausea and possibly vomiting and sometimes hallucinations, muscle jerking, itching, sweating, difficulty urinating. Many of these can be prevented or managed through the use of another medication and some may actually clear up after the first few days.

PAIN MANAGEMENT cont'd

Common Myths About Narcotic Use

Myth:

Giving morphine or other opioids on a regular basis will turn the person into an addict.

Fact:

Opioids are highly addictive drugs. However, when used to manage physical pain under the care of a physician, it is possible to take the medication without becoming addicted. Keeping a steady low dose of pain killer in the body reduces the roller coaster ride of a large dose being introduced, waiting for it to wear off, introducing another large dose and then waiting again. When used in a medical setting with a continuous administration, addiction is well below the rate within the general population.

Myth:

If you use morphine now, it won't work later when your pain is worse.

Fact:

Morphine and other opioids are given in doses appropriate for the level of pain at the time. As pain increases, the amount of the drug may also need to be increased or the drug changed. The increased dosage is reflective of the increase in pain, not in the decrease of effectiveness of the drug.

Myth:

Narcotics can only be given for so long.

Fact:

Morphine and other narcotics are usually given in the last few days or weeks of life. However, there are some cases where the pain level is very high long before the end of life (months or even years). When prescribed, administered and taken appropriately, these drugs can be effective for several years.

PALLIATIVE PERFORMANCE SCALE (PPSv2)

1/4

PPS LEVEL	AMBULATION	ACTIVITY & EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUS LEVEL
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduce	Unable normal job/work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy +/- confusion
20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
10	Totally bed bound	Unable to any activity Extensive disease	Total care	Mouth care only	Drowsy or Coma +/- confusion
0%	Death				

INSTRUCTIONS FOR USE OF PPS

PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient, which is then assigned as the PPS% score.

1. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.
 - i. Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.
 - ii. Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although, this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.
 - iii. Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'
2. PPS scores are in 10% increments only. Sometimes, there level. One then needs to make a 'best fit' decision. Choosing a 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
3. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.
- 4.

Copyright©2001VictoriaHospiceSociety

INSTRUCTIONS FOR USE OF PPS cont'd

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation

The items 'mainly sit/lie,' 'mainly in bed,' and 'totally bed bound' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs. need to lie down.

'Reduced ambulation' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on his or her own but at PPS 60% needs occasional assistance.

2. Activity & Extent of disease

'Some,' 'significant,' and 'extensive' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 13 holes to 9 holes, or just a par 3. or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (e.g. trying to walk the halls).

3. Self-Care

'Occasional assistance' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'Considerable assistance' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat on his or her own accord.

Courtesy Victoria Hospice Society
RESOURCES: BCHPCA Facilitator's Guide

INSTRUCTIONS FOR USE OF PPS cont'd

Definition of Terms for PPS

'Mainly assistance' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'Total care' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake

Changes in intake are quite obvious with 'normal intake' referring to the person's usual eating habits while healthy. 'Reduced' means any reduction from that and is highly variable according to the unique individual circumstances 'Minimal' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious Level

'Full consciousness' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc.

'Confusion' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies.

'Drowsiness' implies fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor.

'Coma' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24-hour period. ©

Copyright Notice.

The Palliative Performance Scale version 2 (PPSv2) tool is copyright to Victoria Hospice Society and replaces the first PPS published in 1996 [J Pall Care 9(4): 26-32]. It cannot be altered or used in any way other than as intended and described here. Programs may use PPSv2 with appropriate recognition. Available in electronic Word format by email request to judy.martellcaphealth.org

Correspondence should be sent to Medical Director, Victoria Hospice Society, 1900 Fort St, Victoria, BC, V8R 1J8, Canada

Nanaimo Community Hospice Society Volunteer Training Program
DEATH & DYING

THE PHYSICAL PROCESS OF DYING

The Palliative Performance Scale (adapted from Hospice Victoria)

The Palliative Performance Scale developed by Hospice Victoria is a new tool for measurement of physical status in palliative care. As a result of having this tool, one can more readily profile the general physical condition of a patient and plan the supports and services they may need.

Critical Levels on the P.P.S.

P.P.S. of 60 - 70%

A person is still at the stage when diversion is important (e.g. outings, massage, music, humour, movies/videos, visiting).

P.P.S. of 50%

This is a level of great transition. Reality of the disease process sets in. Spiritual shifts occur; hope is refocused; fear of dying an issue: good time to establish relationships. There is a need to feel safe, have feelings validated, review their life, and balance energy use. Family may be overwhelmed with needed care. Patient and family need information.

P.P.S. of 40%

Similar issues, Family also needs continued support

P.P.S. of 30%

Another level of transition. Due to further physical changes independence becomes a big issue. Feels closed in, is less talkative, with little future prospects. There is a fear of death and a need for information. Both patient and family may accept the inevitability of death on one level but don't wish to let go.

P.P.S. of 20%

At 20% the body doesn't process water. Food and drink is not desired: Sleep most of the time: Encourage families to feed the spirit rather than the body; stay with the patient and remember with him/her. Empower the family with information. Patient may arouse if it is important enough to do so (e.g visit of loved one). May communicate in a symbolic way, which can have a positive affect on family (e.g. grandmother is packing to go on a trip).

THE PHYSICAL PROCESS OF DYING cont'd

Palliative Performance Scale (PPS) and Psychosocial Care

Psychosocial care of dying patients and their families includes emotional, spiritual, and practical support and counseling through the process of dying, death and bereavement. It is generally thought of as a key component of palliative care. However, delivery of this service is often inconsistent and not always based on a thorough assessment of patient and/or family issues, needs and wishes. This may result in psychosocial care that is uneven, based on problems rather than on an integrated approach of caring.

The counseling team at Victoria Hospice is always looking for ways to improve the consistency, coordination and quality of the psychosocial care provided to patients and families. To enhance communication with one another and our many medical teams we began to include the Palliative Performance Scale (PPS) both in the completion and discussion of psychosocial assessments. In using the PPS, we have become increasingly aware of the timing and relationship between physiological and psychosocial issues; that changes in mobility and functioning are closely tied to spiritual, social and emotional struggles. This information further cements our understanding of and commitment to ensuring holistic care. Identifying critical transitions allows us to use our limited counseling resources more efficiently and effectively.

The tool also provides another avenue for communicating with medical team-mates about changing psychosocial care needs and draws staff attention to expected or predictable patient and family issues and concerns – the process of dying and grief becomes normalized. This section presents the key transition points that occur along the continuum of a terminal illness from 50% PPS through to death and is summarized in Table 17.5 below. It looks at basic physical changes, emotional, spiritual and communication issues for the patient and family, as well as psychosocial interventions. These include planning for care, teaching, mediation and counseling.

PPS	Person	Physical	Emotional	Intake	Communication
50%	Patient Family	Symptomatic, decreased energy Poor self-care	Need to engage, spiritual questions Overwhelmed, feeling helpless	Decrease in appetite, interest	Difference in coping arise
30%	Patient Family	More dependence, key body changes Fatigued	Worn out, closure/endings important Strengths & struggles intensify, lots of questions	Small amounts	Often impeded
10%	Patient Family	Unresponsive, systems shutdown 'Auto-pilot,' exhausted	Possible agitation, refocusing Focusing on death, relief & sadness/anger	Mouth care only	Hearing & touch decline
0%	Patient Family	Dead	Varying needs, reactions		

Table 17.5

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 50%

A. The Patient

1. Symptoms and Responses

At a PPS of 50%, the disease re-declares itself, often with metastatic spread to bones, lungs or other tissues. As a result, the patient experiences an increase in symptoms and body changes. A decreasing energy level results in the curtailment of normal activities meaning reduced mobility, walking with aids or assistance, and less stamina for chores or outings. Patients usually are aware of a loss of appetite and interest in food, unless they are on dexamethasone, which increases appetite.

When the reality of disease sets in, a patient finds that earth-shattering psychosocial changes and shifts are triggered. The prospect of cure is unlikely. Along with a loss of control and autonomy come shifts in family roles and responsibilities. This is a time of overwhelming and mixed emotions; panic, confusion, fear, resignation, helplessness, hopelessness.

Patients face fears of suffering and dying. Spiritual questions arise about the meaning of life and meaning of death. There is a shift in hopes, dreams and expectations. Patients have a need to continue engaging with life in a meaningful way through activities that have particular value for them, such as, pursuing alternative healing methods, holding on to hope, or maintaining social contacts and relationships.

At this time, the difficulties that arise tend to be based on pre-existing family style and patterns.

Between patient and family there will be differences in grieving process, and issues around dealing with illness or expected death can surface.

2. What Helps

Planning: Involvement in planning for care, family future, and other issues can help patients maintain areas of control. Decision making about palliative care and symptom management often occurs at this point, PPS 50%.

Teaching: Information about supports and resources available [medical, emotional, spiritual, practical], in the time ahead, is helpful at this time.

Counselling: Building a solid, safe relationship is important now, as is information and support to address feelings of being overwhelmed. Offer available resources; ensure beliefs and understanding are accurate; consult with appropriate team members.

Begin to explore what lies ahead. Determine what is predictable and known, and what cannot yet be known; explore fears of dying, of pain and of suffering. Exploration and validation of feelings and emotions can help to give reassurance and normalize their experience. Life review and reminiscence offer meaning and perspective to present circumstances.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 50% cont'd

B. The Family

1. Responses

When the patient is at PPS 50%, the family often are unable to recognize the physical impact on themselves of providing care to the patient. They may be unable to pace themselves, feeling totally responsible, wanting to maintain control, and unaware of the demands of ongoing care. These factors often lead to poor self-care, especially through poor sleep, nutrition, and lack of exercise.

Similarly to the patient, when reality of the disease sets in, major psychosocial changes and shifts are also triggered within the family. As the prospect of cure is recognized as unlikely, shifts in family roles and responsibilities take on new significance.

This is a time of overwhelming, often mixed emotions. Families may be needing information and/or a prognosis but afraid of the answers, feeling unsure and insecure. Despite having fears of the future, they are starting to plan for it. As the focus on the patient's needs and situation increases, less importance is placed on family members' own feelings and concerns. They put their own needs on hold, in part to protect the patient.

The impact of the disease may become more apparent to the children in a family, prompting questions, fears, and changes in behaviour.

2. What Helps

Planning: This is when family need to be talking to the professional caregiving team; to get information about the disease process, to plan for help with care, to coordinate resources. Family conferences are an excellent way to get everyone involved directly discussing concerns, needs and plans.

Teaching: There is a lot of new information to be absorbed during this time; information about resources and care options that are available in the community, the workings of the various systems family must deal with, and self care issues and approaches.

The adults may need information about children's understanding of illness and their developmental needs; modelling of appropriate attitudes and language may help. Direct support may be appropriate.

Counselling: A number of areas need to be addressed with family. Intense feelings of being overwhelmed by changes in disease and condition may need to be explored and supported. Fear of not knowing what lies ahead and loss of control need to be discussed. The family's ways of dealing with this new reality [denial, avoidance, hope, acceptance] need to be acknowledged. The impact on the family and its functioning brought about by changes, needs to be addressed in terms of the dynamics of the family in the present situation.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30%

A. The Patient

This is a time when changes become more predictable, more apparent and closer together. Often the time frame, of remaining life and approaching death becomes clearer. Symptoms, such as pain, continue to change, requiring adjustments or increases, and possibly, admission to hospital or palliative unit for effective management.

The patient's body may begin to look noticeably wasted, unless medications cause increased appetite or fluid retention. Activity levels decrease dramatically. The patient is totally bed bound and doesn't get dressed, although they may get up to the commode or lounge chair.

They are increasingly dependent on others for care such as feeding, drinking and re-positioning. Energy continues to decrease and there is little desire or ability for socializing, except with immediate family or friends.

As the disease progresses and its impact continues to be felt, the patient may experience waves of helplessness and hopelessness. The ability to adjust to the dramatic changes now, the loss of independence and control, will depend on how well the patient was able to accept and move through the psychosocial shifts that occurred at PPS of 50% and 40%.

Concerns about dependency and being a burden to others often arise with the recognition of increasing care needs. The patient can feel emotionally worn out, tired or drained and often experiences increased periods of drowsiness, sleepiness and confusion. They may begin to think about letting go - of life, of the fight, of worries.

Along with this, unresolved concerns can become an emotional burden and there may be a sense of urgency to bring closure to these issues. This is the time when a shift from fearing death to an acceptance of death often occurs for the patient.

At this PPS level, intake will be significantly reduced to small amounts of soft or liquid foods, such as food supplements or a few spoonfuls of soup, ice cream, and yogurt.

The patient's conversations are often impeded by sleepiness, wandering attention, and lack of focus or energy. Also, the patient may find it hard to discuss their fears or feelings with family due to the family's usual communication style and boundaries.

At this time, the patient and family may find themselves in very different places along the acceptance denial continuum, making communication difficult between them. This is affected by the patient and family having different opinions, concerns or feelings about care, different hopes or expectations, and different information. The patient is often more familiar with the reality of their disease and its progression than is the family.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30% cont'd

A. The Patient cont'd

2. What Helps

Planning: It is helpful to the patient that attention is given to addressing family support during and after death. Concerns often include reviewing practical matters, such as will, power of attorney, and funeral/memorial planning, especially if these matters have not already been attended to. This is a time to re-evaluate plans for care and death: the patient will choose their level of participation in this process. Discussion about family visiting or attendance during the time that remains is important.

Teaching: The patient will appreciate helpful hints on adjusting their life style to suit changed abilities and energy levels. Times spent conversing with the patient or addressing issues will need to be managed according to the energy levels of the patient. This is a time to introduce and provide opportunities for the patient to experience the benefits of touch therapies, guided imagery, and relaxation.

Information about individual differences, in terms of coping, grieving, and processing one's experience, and information about family systems, in terms of communication and the roles of children, can ease tensions for the patient in relation to the family.

Counselling: The patient may wish to explore the meaning of life and death through expressing their thoughts and feelings about death, dying and spirituality. This can include exploration of religious concerns or beliefs with a spiritual counsellor or leader. As fears and concerns are explored, appropriate reassurance can be provided about the dying process, emotional and physical suffering, and separation. Assistance can be given to facilitate some kind of closure for unfinished business, whether that is resolution, letting go, or acceptance of the situation that causes distress.

Offer times for the identification, acknowledgement, and expression of the losses experienced through the progression of the disease.

Mediation: The patient may appreciate help to address differences with or within the family.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30% cont'd

B. The Family

1. Responses

The family continue to be fatigued and weary through responding to the various demands of the situation. Family will be dealing with a dilemma – how to start separating emotionally from the patient, while wanting to be physically present and needing to be more involved in care. They are also attending to current and ongoing family needs and making necessary arrangements for the approaching death and the future thereafter.

As stress increases, different coping styles, personalities, life experiences influence family relationships and dynamics, often quite dramatically.

Children, similarly to other family members, adjust according to life experience, developmental level, available support and information, and their ongoing involvement with the patient.

At this time, family may struggle when patient begins the process of letting go as they perceive this as giving up or giving in. Family caregivers may reach the end of their tether, physically or emotionally, becoming overwhelmed by the demands of care and no longer able to manage. Requests for admission into a care facility or for increased home supports are common at this level.

Family may want a prognosis or time frame now as they shift from long-term hopes to wanting the patient to live until a particular day or event, or until the arrival of certain family members. Concerns are often expressed about how to handle out-of-town family who may need time to adjust and integrate the changes.

When the patient is at PPS 30%, pre-existing family strengths and stresses are intensified or heightened as they cope with the situation. Their ability to support and work together and their individual personalities and coping styles will be apparent.

2. What Helps

Planning: As the care needs of the patient increase, it is important to help the family to Liaise with Home Care Nursing, Long Term Care, and/or the palliative team for ongoing care. Plans for unit admission or increase in home supports should be discussed in terms that are realistic considering the wishes and abilities of both the patient and family. Offer information that allows family to make decisions, which require a specific timing, i.e., planning events or family visits.

Teaching: It is helpful to model and support care for the patient and the family that includes therapeutic touch, gentle massage, and relaxation techniques.

Information about symbolic communication, reduced consciousness, or patient withdrawal, can help to prepare family for the changes ahead.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 30% cont'd

B. The Family cont'd

Counselling: At this juncture, it is imperative that channels of communication are kept open to ensure that information is shared and questions are addressed. Ensure that questions about the disease, prognosis, medications are asked and that answers are understandable. Family will need support around the issues of out-of-town family, symbolic language and prognosis. There may be specific fears or incorrect assumptions about starvation and dehydration as the patient becomes unable to eat and drink so that reassurance about reduced intake must be provided. Be open to attend to any further concerns and issues that may arise at this time.

Talking about family self-care, that is individual and mutual self-care, is critical for their physical and emotional health, now and after the death. Help parents and other family members to understand children's needs and behaviours, at this time. Families find it helpful and positive to explore hopes and dreams in the context of the current situation. Reframing the tasks that they are facing, like letting go and making adjustments, help family to gain new perspectives on their experience and the situation.

Mediating: Family may need and want help to deal with misunderstandings and issues that arise.

Psychosocial Care at PPS 10%

A. The Patient

1. Symptoms and Responses

Over the decline from PPS 30% to PPS 10%, the impact of the disease on the mind becomes increasingly noticeable. Both the mind and body are weakened due to the toxic effects of the disease. Increased drowsiness and sleep due to the burden of the disease are part of the weakness and withdrawal experienced by the patient. These drastic physical changes will have required adapting care through changes in medication routes, use of catheters, and increased personal care.

When the patient is at a PPS of 10%, they are usually unresponsive, in a state of continuous sleep or coma, and do not wake when touched or spoken to. There are increasing signs that different body systems are shutting down: the pulse becomes irregular and weak; breathing patterns are increasingly irregular and shallow; breath sounds moist; the skin is cool to touch and pale bluish grey in colour or even mottled looking. There is limited or no output 24-48 hours prior to death.

If the patient displays occasional unexpected agitation, which is not directed at anything observable, consider whether it may be expressions of thoughts and feelings, or completion of some necessary internal work. The patient, at this point, may be focusing on the journey ahead of them, that is, the transition of leaving the body.

At this time, only mouth care is provided.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 10% cont'd

A. The Patient cont'd

Levels of consciousness or mental functioning can vary so that patients may be alert until moment of death, move between levels of consciousness, or become increasingly drowsy. There may have been moments of alertness in which the patient roused to say a few words or communicate using symbolic language. Such efforts to communicate may be increasingly difficult to understand. Predeath restlessness is common and is sometimes interpreted as confusion or poor symptom management.

Although either verbal or non-verbal communication is rare when a patient reaches a PPS of 10%, the patient does maintain their connection with the people around them through the sense of hearing.

2. What Helps

Counselling: What is helpful to the patient at PPS of 10% is to respond to whatever seems to be offered in the moment. Approaches such as therapeutic touch, Reiki, guided imagery and gentle massage allows the patient to receive support in a non-demanding way. Be present and comfortable, and speak quietly.

Acknowledge and validate any metaphorical communications by listening and trying to understand their meaning, rather than dismissing them. Family often are able to interpret these communications from their intimate knowledge of the patient.

B. The Family

1. Responses

The family may be operating on “auto-pilot,” as they are exhausted physically and emotionally. They experience increasing difficulties with sleep, relaxation and taking time away as they may prefer to be continually by the patient’s bedside. There is an increased risk of injury or broader health consequences for family caregivers at this time due to physical stressors and general self-neglect. Some families arrange a rotation of family visiting to allow for some rest. Often family members experience loss or increase of appetite, causing a disruption of usual eating patterns.

Families will have struggled with a number of emotional conflicts as this time approached.

Their awareness that death will be soon conflicts with not being ready to let go. They may be wanting the death to occur, yet holding on; wanting suffering to be over, yet not wanting the person to die. They may be feeling angry or relieved about the death, yet guilty about wanting the death to come soon.

There may be a range of feelings about the death, from letting go, to holding on, to withdrawal. An increased awareness of the impending losses and life without the patient is common. If the dying process has lingered on, family may feel extremely weary and empty. Feelings of abandonment may occur at being excluded by patient’s withdrawal. Some family may have feelings of fear and anxiety about being present at time of death. As death approaches, family who are aligned with what is happening may experience a profound sense of peacefulness. At the time of death, feelings of relief are common, accompanied by feelings of sadness and loss.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 10% cont'd

B. The Family cont'd

2. What Helps

Planning: This is the time to plan for death: gathering family, discussing what to expect, and reviewing what to do when death occurs. In preparation for death, plan what needs to be done, including a review of funeral planning, keeping both patient wishes and family needs in mind.

Teaching: Model respectful behaviours by speaking directly to the patient to acknowledge their presence and addressing them by name.

Providing information on the dying process is very important. Family need to know about physical changes that indicate death is approaching, about communication with the patient and among themselves, and about choices concerning what they want to do at the time of death.

Counseling: It is helpful to listen to and normalize feelings of loss, abandonment, and fear. Offer opportunities for family to talk about present thoughts, concerns and feelings. This time can be an opportunity for life review and reminiscence, for humour as well as sadness.

Ensure children are included in ways that are comfortable for them and that their questions are answered, their presence is encouraged, and that they have space where play is permitted.

Acknowledge the family's grief: provide support and information about what is normal at this time. Part of this will be to address the fears or concerns there may be about being present at the time of death. It is helpful at this time to acknowledge and validate differences amongst family members as each person has their own particular grief process, readiness for death, and their own feelings about their person dying. If necessary, address emotional conflicts: give information and opportunities for expression.

Mediating: This is a time to check out any unfinished business family members may have with the patient or with each other that is affecting their ability to be present and peaceful.

Psychosocial Care at PPS 0% Time of Death

The Family

1. Responses

The family may have varying needs at this time. For example, they may wish to stay close to the person who died and have private time with them. Time to say goodbye may include prayers or rituals, preparation of the body, reminiscing and spending family time. It is common for family to repeatedly check the body and review the time of death. Sometimes family will not want to be in the presence of the body but will want time for these same closure activities.

THE PHYSICAL PROCESS OF DYING cont'd

Psychosocial Care at PPS 0% Time of Death cont'd

The Family cont'd

2. What Helps

It is helpful to provide opportunities for family to acknowledge their particular needs at this time. As mentioned above, these may include time with the deceased, preparing the body, rituals, prayers, and saying goodbye. Opportunities for family to come together and support one another in a comfortable way will be appreciated. Privacy, respect, unlimited time, and easy access to the deceased are aspects that need to be considered.

This is a time to review information about the steps to be taken in completing funeral arrangements. Provide information about the grieving process and normalize what the family members are experiencing. It will be helpful to let family know how to access bereavement services. Both grief handouts and discussion are helpful sources of information. Written information is appreciated as it can be referred to later, in a less stressful moment.

THE DYING PROCESS ~ FINAL HOURS

The physical and mental changes that you will be seeing may seem frightening and distressing. The guest may experience a variety of changes. Each person's death is different. Changes may occur quickly or slowly, may appear and then disappear only to reappear again. People die when they are ready.

Many feelings expressed in the last few days are part of the grieving process, both for the dying person who mourns for her/himself and the family who grieve the loss. Although sadness is common, many people who believe in eternal life are happy to see God or those who have died before them. For them, death is comforting and reassuring.

In general, people die as they have lived. If a person is cheerful and copes well, then s/he will probably approach the end of life in the same way.

Usually within the last 3-6 days of someone's life, the person is less hungry and their body can no longer process food. The person will eat very little, or have a total lack of interest in food. The body is shutting down and no longer requires nutrition. Fluid intake continues, but usually not to the point of death. The person becomes unable to swallow and mouth care is needed at this point. Due to the lack of fluid intake, urine output decreases and becomes more concentrated. Bloating, water retention and swelling can also occur.

Changes in strength and awareness are other signs of death. The person may drop things or experience twitching and jerking of their hands and legs. The jerking and twitching will be most noticeable to caregivers and family, more so than to the person who is dying. Weakness increases. The person may shift in their experience of reality. They may talk to someone who is not present, or relate that they have seen someone who is dead. They may talk of a bright light. They may appear unaware of who is with them. The person can also appear confused, repeating sentences that do not seem to make sense. Some people become restless, pull at their bed linens and/or try to get up. This is known as 'pre-death restlessness'.

The person will start sleeping longer and sometimes have trouble waking or responding. The person may have a fixed stare and can become non-verbal.

Changes in breathing are common. There can be a period of 6 – 12 hours where they have very rapid breathing. Breathing can become irregular and shallow. Sometimes there are periods when breathing can stop for 30 seconds or so and then start again. Moist breath that bubbles or gurgles is common as mucous collects in the throat and lungs. This is called the 'death rattle'. This noise is often troubling to family and friends, less so to the dying person.

All senses start to fail and hearing is the last to go. Always assume the dying person is alert and can hear everything you say.

The dying person's circulation will slow and the body temperature will drop. The skin may become cool and clammy.

Most people die by slipping into a coma before the moment of death.

Active Dying can take hours or days. Even when many of the signs are present, it is not always possible to predict when death will occur. These ups and downs can be emotionally and physically draining on the family and caregivers.

Summary of Signs of Death

- Sleeps longer, sometimes having difficulty waking. Eventually slips into coma
- Reduced intake of fluid and food
- Appears confused, does not recognize familiar people or surroundings
- Weakness becomes profound, difficulty responding verbally, difficulty swallowing or forgetting to swallow
- May have a fixed stare
- Breathing becomes irregular and shallow
- Periods when breathing stops and starts
- Breathing is moist, may develop a rattle, may gasp for air
- Pulse becomes irregular, weak, then absent
- Hands and feet become cool
- Skin color may be pale, bluish or mottled
- Urine output will decrease or even be absent for 24-48 hours
- May lose bladder control
- Bowel movements may be absent, or uncontrolled oozing of soft or liquid stool

Family Response

During the last few days, family members may wish to stay with their loved one 24 hours a day. Sometimes they may need to tell the dying person it is okay to die.

After the death, family members may show signs of relief, exhaustion, and sadness. Reactions are varied and individual.

Encourage the family to spend time with the deceased. There is no rush to act at this point. The doctor will need to be called to verify the death and the funeral home will need to be called to come and pick up the body, but it does not have to be done immediately.