Practice Support Program

PSP End of Life Care Algorithm

Ver 8.5 May 2018

Identify and Create Registry

- "Surprise Question"
- Choice or Need for Comfort Care
- Clinical Indicators
- Sentinel Events

Assess

- Seniors Assessment Tool
- Palliative Performance Scale (PPS)
- Edmonton System Assessment Scale
- Goals of Care
- Domains of Care

GPAC Part I – Approach to Care

Manage Symptoms

- GPAC Part II – Pain and Symptom
- Fraser Health Symptom Guidelines

Attention to symptom distress can be early in the illness trajectory & should not be linked with prognosis.

Would not be surprised if patient died in the next year

Prognosis approximately 6 months and PPS 50%

Concern about ability to support client at home given increasing care needs

Anticipating death in the next few days or weeks

Death and Bereavement

Plan and Collaborate

Transition 1
Disease advancement

ROLES

- Recognition and registry
- Advance Care Planning
- Identify client's values and beliefs
- Clarify illness trajectory, possible complications, prognosis, expected outcomes to inform goal
- Consider need for referral/ coordination with H&CC

- How to Break Bad News
- Advanced Care Planning Questions
- My Voice – Including initial conversation
- End of Life Care Plan templates

Transition 2
Decompensation, experiencing life-limiting illness

ROLES

- Discuss care coordination
- Consider hospice palliative care referrals

- BC Palliative Care Benefits Registration
- Medical Supplies and Equipment
- Palliative Care Drug Formulary
- H&CC/ Palliative Care forms
- No CPR Form
- Family Meeting
- EI Compassionate Care Form

Transition 3
Dependency & symptom increase

ROLES

- End of Life Care Planning, including assess for preferred location for care

- EoL Care Checklist
- Home Death Protocol
- Notification of Expected Death at Home
- What to consider when caring for someone dying at home
- Caregiver Resources

Transition 4
Decline & last days

ROLES

- Discuss meds required in home with HCN
- Assess pt/family are comfortable with their EoL care plan and support required changes

- "When Death is Close at Hand"
- Online Resources

Transition 5
Death & Bereavement

ROLES

- Have follow-up bereavement visit/ call and send condolence card to family

- Death Certificate
- Bereavement
- GPAC Part III - Grief & Bereavement

Return to Page 1

Three triggers for Supportive/ Palliative Care are suggested - to identify these patients we can use any combination of the following methods:

1. The surprise question 'Would you be surprised if this patient were to die in the next 6-12months' –

Surprise Question

This question was developed by Pattison M, Romer AL: Improving care through the end of life: Launching a primary care clinic-based program. J Palliat Med 4 :249– 254, 2001.

This is an intuitive question integrating co-morbidity, social and other factors. If you would not be surprised, then what measures might be taken to improve their quality of life now and in preparation for the dying stage. The surprise question can be applied to years/months/weeks/days and trigger the appropriate actions at each stage ie "the right thing to happen at the right time"

Return to Page 1

2. Choice/ Need - The patient with advanced disease makes a choice for comfort care only, not 'curative' treatment, or is in special need of supportive / palliative care eg refusing renal transplant

Indicators

3. Clinical indicators - Specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frail/ dementia

Return to Page 1

Specific clinical indicators of advanced disease

These clinical prognostic indicators are an attempt to estimate when patients have advanced disease or are in the last year or so of life. These are only indicators and must be interpreted with clinical judgement for each individual patient, but they can help to alert clinicians to the need for extra supportive are. They have been drawn from a number of expert sources from the UK and abroad, and are updated regularly. Some use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore act as a rough guide to indicate to those in primary care and in secondary services that patients may be in need of palliative / supportive care. Primary care teams may include these patients on their Supportive/palliative care registers and hospital staff may suggest to GPs in discharge letters that such patients are included on the registers, if helpful.

Next -->

Return to Page 1

Co-morbidities or other General Predictors of End Stage illness

Co-morbidity is increasingly the biggest predictive indicator of mortality and morbidity. Also-

- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status / ECOG/Karnofsky score (KPS) < 50%. Dependence in most activities of daily living(ADLs)

1. Cancer Patients

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less. More exact predictors for cancer patients are available elsewhere on the GSF website.

2. Organ Failure Patients

Heart Disease – CHF

At least two of the indicators below :-

- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

Chronic Obstructive Pulmonary Disease

- Disease assessed to be severe e.g. (FEV1 <30%predicted – with caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria

Next -->

Return to Page 1

▪ MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness

▪ Signs and symptoms of right heart failure

▪ Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression

▪ >6 weeks of systemic steriods for COPD in the preceding 12 months

Renal Disease

▪ Patients with stage 5 kidney disease who are not seeking or are discontinuing renal replacement therapy. This may be from choice or because they are too frail or have too many co-morbid conditions.

▪ Patients with stage 5 chronic kidney disease whose condition is deteriorating and for whom the one year 'surprise question' is applicable ie overall you would not be surprised if they were to die in the next year?

▪ Clinical indicators:

▪ CKD stage 5 (eGFR <15 ml/min)

▪ Symptomatic renal failure -Nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload)

▪ Increasingly severe symptoms from comorbid conditions requiring more complex management or difficult to treat

NB. many people with Stage 5 CKD have stable impaired renal function and do not progress or need RRT.

Neurological Disease

a) Motor Neuron Diseasese

MND patients should be included from diagnosis, as it is a rapidly progressing condition Indicators of rapid deterioration include:

▪ Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest

▪ Barely intelligible speech

▪ Difficulty swallowing

Next -->

Return to Page 1

- Poor nutritional status
- Needing assistance with ADL's
- Medical complications eg pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry)

b) Parkinson's Disease

The presence of 2 or more of the criteria in Parkinson disease should trigger inclusion on the Register

- Drug treatment is no longer as effective / an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with "off" periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

c) Multiple Sclerosis

Indications of deterioration and inclusion on register are:-

- Significant complex symptoms and medical complications
- Dysphagia (swallowing difficulties) is a key symptom, leading to recurrent aspiration pneumonias and recurrent admissions with sepsis and poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia
- Breathlessness may be in the terminal phase

3. Patients with Frailty and Dementia

- Multiple comorbidities with signs of impairments in day to day functioning
- Deteriorating functional score eg EPOC/ Karnofsky

Next -->

Return to Page 1

▪ Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, reduced weight loss, self reported exhaustion

Dementia

▪ Unable to walk without assistance, and
▪ Urinary and fecal incontinence, and
▪ No consistently meaningful verbal communication, and
▪ Unable to dress without assistance
▪ Barthel score < 3
▪ Reduced ability to perform activities of daily living

Plus any one of the following:

10% weight loss in previous six months without other causes, Pyelonephritis or UTI, Serum albumin 25 g/l, Severe pressure scores eg stage III / IV, Recurrent fevers, Reduced oral intake / weight loss, Aspiration pneumonia

Stroke

▪ Persistent vegetative or minimal conscious state / dense paralysis / incontinence
▪ Medical complications
▪ Lack of improvement within 3 months of onset
▪ Cognitive impairment / Post-stroke dementia

Return to Page 1

Sentinel Events

The term *sentinel event* was originally and is still commonly defined as any unanticipated event in a healthcare setting resulting in death or serious physical or psychological injury to a patient or patients, not related to the natural course of the patient's illness.

However, in the context of care for patients with advanced disease and approaching end-of-life, the term is now also used to describe events in the disease process that should trigger discussions around goals of care. After the diagnosis of cancer, best practice in cancer care identifies the following examples of sentinel events that occur within the disease trajectory: initiation of invasive procedures such as mechanical ventilation; first diagnosis of CNS disease; initiation of a new chemotherapy regimen; and decision to undergo major surgery. (Walling 2008)[1] Sentinel events can be identified for other advanced illnesses, for example, renal, cardiac, respiratory and dementia.

These sentinel events are important opportunities to review advance care planning and readdress a patient's goals, given the changes in prognosis and increased risk for being in a state in which the patient will not be able to make treatment decisions themselves. Necessarily, these events will also provide opportunities for reflection and can be used to initiate conversations.

Sentinel events questions/comments:

- "Well, that was a close call. What were you thinking about when this happened?"
- "What if things don't go so well the next time?"
- "How did your family do during this time?"

[1] Walling, A., Lorenz, K., Dy, S., Naeim, A., Sanati, H., Asch, S., Wenger, N. Evidence-Based Recommendations for Information and Care Planning in Cancer Care. *Journal of Clinical Oncology*. August 10, 2008,; 26: 3896-3902.

Victoria Hospice

Palliative Performance Scale (PPSv2) version 2

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 with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	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 do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. 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.

2. 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.

   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%.

   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.

   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.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.

4. 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.

Palliative Performance Scale (PPSv2) version 2. *Medical Care of the Dying, 4th ed.;* p. 120. ©Victoria Hospice Society, 2006.

Next -->

Return to Page 1

Victoria Hospice

Palliative Performance Scale (PPSv2) version 2

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 their 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 18 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 (eg. 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 of his or her own accord.

'**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 either 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.

Palliative Performance Scale (PPSv2) version 2. *Medical Care of the Dying, 4th ed.;* p. 121. ©Victoria Hospice Society, 2006.

Print

Return to Page 1

Capital Health

CARITAS HEALTH GROUP

Edmonton Symptom Assessment System: Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name _____

Date _____ Time _____

Complete by *(check one)*

- ☐ Patient
- ☐ Caregiver
- ☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

Click for Pain & Symptom Dairy

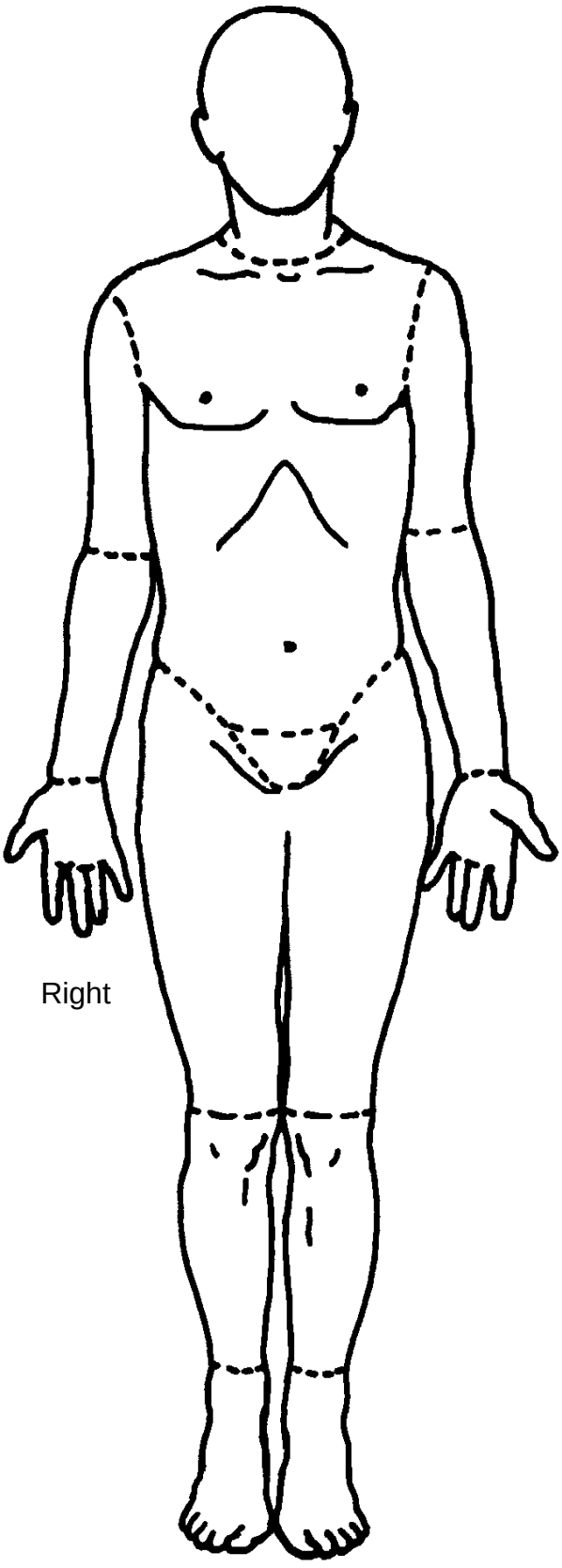
CH-0202 May 2001

Click for Instructions

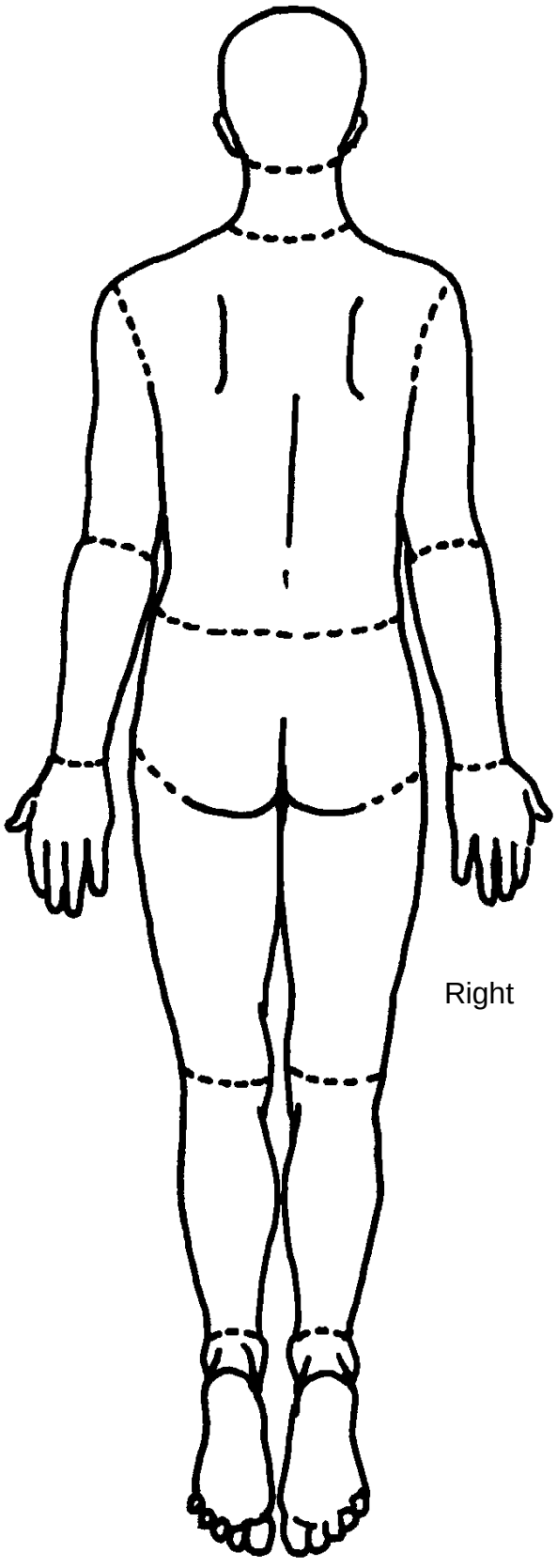
Next -->

Return to Page 1

Please mark on these pictures where it is you hurt.



Right



Right

Return to Page 1

Guidelines for using the Edmonton Symptom Assessment System (ESAS)

Purpose of the ESAS

This tool is designed to assist in the assessment of nine symptoms common in cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath, (there is also a line labelled “Other Problem”). The severity ***at the time of assessment*** of each symptom is rated from 0 to 10 on a numerical scale, 0 meaning that the symptom is absent and 10 that it is of the worst possible severity. The patient and family should be taught how to complete the scales. It is the patient’s opinion of the severity of the symptoms that is the “gold standard” for symptom assessment.

The ESAS provides a clinical profile of symptom severity over time. It provides a context within which symptoms can begin to be understood. However, it is not a complete symptom assessment in itself. For good symptom management to be attained the ESAS must be used as just one part of a holistic clinical assessment.

How to do the ESAS

The patient circles the most appropriate number to indicate where the symptom is between the two extremes.

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

The circled number is then transcribed onto the symptom assessment graph (see “ESAS Graph” below).

Synonyms for words that may be difficult for some patients to comprehend include the following:

Depression	-	blue or sad
Anxiety	-	nervousness or restlessness
Tiredness	-	decreased energy level (but not necessarily sleepy)
Drowsiness	-	sleepiness
Wellbeing	-	overall comfort, both physical and otherwise; truthfully answering the question, “How are you?”

When to do the ESAS

a) In palliative home care, it is a good practice to complete and graph the ESAS during each telephone or personal contact. If symptoms are in good control, and there are no predominant psychosocial issues, the ESAS can be completed weekly for patients in the home. In hospice and tertiary palliative care units the ESAS should be completed daily. In other settings the palliative consultants will utilize this tool in their assessment on each visit.

b) If the patient’s symptoms are not in good control, daily assessments need to be done in person by the attending health professionals until the symptoms are well-controlled (see “d” below).

c) If symptom management is not attained, or consultation about possible care options is needed, patient assessments by Palliative Care Consultants are available (**attending physician must agree**). Consultative discussions not requiring in-person patient assessments are available from Palliative Care Consultants upon request.

d) If, after all therapeutic options have been exhausted and consensus is reached that a symptom cannot be further improved, visits and assessments can return to their normal pattern for that patient.

(OVER)

Next -->

Return to Page 1

Who should do the ESAS

Ideally, patients fill out their own ESAS. However, if the patient is cognitively impaired or for other reasons cannot independently do the ESAS, then it is completed with the assistance of a caregiver (a family member, friend, or health professional closely involved in the patient's care). If the patient cannot participate in the symptom assessment, or refuses to do so, the ESAS is completed by the caregiver alone.

Note: when the ESAS is completed by the caregiver alone the subjective symptom scales are not done (i.e. tiredness, depression, anxiety, and wellbeing are left blank) and the caregiver assesses the remaining symptoms as objectively as possible, i.e. pain is assessed on the basis of a knowledge of pain behaviors, appetite is interpreted as the absence or presence of eating, nausea as the absence or presence of retching or vomiting, and shortness of breath as laboured or accelerated respirations that appears to be causing distress for *the patient*.

When a patient is irreversibly cognitively impaired and cannot participate in doing the ESAS, the caregiver continues to complete the ESAS as outlined above and the Edmonton Comfort Assessment Form (ECAF) may also be used (see ECAF guidelines).

The method in which the ESAS was completed must be indicated in the space provided at the bottom of the ESAS Numerical Scale and the ESAS Graph as follows:

Bottom of ESAS Numerical Scale

Completed by *(check one)*

Patient ☐
Caregiver ☐
Caregiver -assisted ☐

Bottom of ESAS Graph

Completed by ☐☐☐☐☐☐☐ ←insert appropriate letter from key in date column (date indicated at the top of form)

Key:
P = Patient ☐
C = Caregiver ☐
A = Caregiver -assisted ☐

Where to document the ESAS

The ESAS is always done on the ESAS Numerical Scale and the results *later transferred* to the ESAS Graph. Graphing symptom severity directly onto the ESAS Graph without the use of the numerical scale is not a valid use of the ESAS nor a reliable method of symptom assessment (attention to the graphed historical trend may affect the current scores and so undermine one of the main purposes of the ESAS, i.e. to assess the current symptom profile as accurately as possible).

Other Information About the ESAS

The ESAS Graph also contains space to add the patient's Mini-Mental Status Exam score. The "normal" box refers to the normal range for the patient, based on age and education level (see Instructions for MMSE). As well, a space for the Palliative Performance Scale (PPS) is included. The ESAS is available in other languages and also in faces for those patients who do not read.

Next -->

Return to Page 1

Capital Health

Edmonton Symptom Assessment System Graph
(ESAS)

Date																													
Pain	10																												
	0																												
Tiredness	10																												
	0																												
Nausea	10																												
	0																												
Depression	10																												
	0																												
Anxiety	10																												
	0																												
Drowsiness	10																												
	0																												
Appetite	10																												
	0																												
Wellbeing	10																												
	0																												
Shortness of breath	10																												
	0																												
Other	10																												
	0																												
Mini-Mental (Normal _____)																													
PPS																													
Completed by P = patient C = caregiver A = caregiver-assisted																													

Level of Education _____

Cage Score _____

Return to Page 1

DISCUSSING Goals of Care

Adapted from LEAP Courseware, version 1.1

1. **What are some common goals of care? What other topics need to be covered in EOL discussions?**

- ***Goals of treatment**: **Disease orientation***
  - Cure
  - Control of disease = remission
    - More time/Life prolongation
  - Symptom control/management
    - Enabling patient function
  - "Quality of life"
    - Relief of suffering
    -
- **Goals of care: *Patient/family orientation.***
  - What are your beliefs and values?
  - Have you had previous experience with death? With dying?
  - What are your *goals of care?* Examples:
    - Maintaining and improving function
    - Staying in control
    - Relief of suffering
    - Pain and symptom management
    - Quality of life/ Living Well
    - Preferences for location of care
    - Relieving burden for family members
    - Prolonging life for as long as possible or until a specific event (Time limited trials of care)
    - Life closure/ Dying well
    - Preferences for location of death

- **Discussion of Specific interventions**:
  - Advanced directives
  - Health care proxy (decisions about treatment issues)
  - Enduring power of attorney (financial issues)
  - Do not resuscitate (DNR) orders
  - Creating opportunities to address unfinished business

Quill T. JAMA. 2000; 284:2502-2507.

2. **How would you suggest code status preferences be discussed with patients? What are the issues?**

Best practice approach: Initiate code status discussions with patients but recommend DNR status, and provide the rationale for that. This gives patients guidance, opens the door to other discussions around end-of-life issues, and places all the individuals affected (patient, family members, loved ones, and members of the health care team) on the same page.

Next -->

Return to Page 1

Step 1: Discuss the goals of care.
"[[Patient's name]], unfortunately your illness is not curable and it is progressing. I wish I could offer you a cure or a treatment that would control the disease, but I can't. I would be lying to you if I said I could. Although I cannot cure or control the disease, I can provide care that is aimed at maintaining the best possible quality of life, and at keeping you comfortable in the time that you have left. How would you feel about this?"

Quill, T. E., Arnold, R. M. and Platt, F. "I Wish Things Were Different": Expressing Wishes in Response to Loss, Futility, Unrealistic Hopes. In *Ann Intern Med,* 135(7): 551-555, October 2, 2001.

"It is important to pose the question: "What are the goals of care now that we cannot cure or control you going to recommend that the care you receive focuses on maintaining the best quality of life possible under the circumstances."
- Do not say: "There is nothing more that we can do".
- Do not say: "Do you want us to do everything?"

Step 2: Gently and sensitively open the discussion
"[[Patient's name]], there is something important that we need to discuss. It is a difficult but important discussion. I want to discuss this not because I think you will die soon (assuming it is not in the situation of an imminent death in which case one would not use this phrase), but because we need to make some decisions to ensure that the care you will receive is consistent with your goals of care. Once the decision is made you can then focus on living as best you can under the circumstances. I also want you to know that, whatever the decision, we will continue caring for you. The decisions we need to make relate to when your heart and lungs stop because of your [name the disease]."

Step 3: State your recommendation
"From the outset, I want you to know that I am strongly recommending that we not try and restart your heart with cardiopulmonary resuscitation when it stops."

Step 4: Explain why you are not recommending CPR, but rather ordering a DNR (do not resuscitate) instead.
"[[Patient's name]], research has shown that in patients with advanced illnesses like yourself, attempting to restart the heart with CPR, using methods such as giving you special drugs, chest compressions, placing a tube in your throat to help you breathe and connecting you to life support machines is almost always unsuccessful. Furthermore, these treatments may prolong your suffering. They do not allow for a natural death. I also want you to know that having a DNR order in place does not stop us from caring for you or you receiving other treatments."

Step 5: Ask if he or she has any questions or concerns about what you have just said. Address these concerns.

3. **How would you respond if you were asked, "How long do I have to live?"**

Next -->

Return to Page 1

Step 1: Validate the question

" This must be an important question for you. Many patients in the same situation have asked the same question. Why is it important for you to know the answer to this?

Step 2: Provide a disclaimer

" We are very inaccurate at predicting life expectancy. We are often wrong. In some cases we overestimate how long patients like you might live while in other cases we underestimate how long you might live. Also because of your advanced disease you are at risk for unexpected events.

Step 3: Provide a rough best estimate – express it in terms of time, such as:

- "days to many days or weeks"
- "many days to many weeks"
- "many weeks to a few months"
- "it is unlikely to be in the order of years any more"

Step 4: Explain that we are often wrong and that it could be much longer or sometimes, unfortunately, shorter

Step 5: Provide assurance of ongoing support and care. May involve referrals

Do not give the assurance unless you can provide this care. Be authentic and sincere. If you cannot provide the care, ensure that the patient is connected with those who can. If, for example, you do not do home visits (which are often needed for those patients who become very frail and are near to the end of their lives), then assist the patient in finding caregivers (physician, nurses, social workers, etc.) who do. If you do not provide a 24-hour, 7-day-a-week patient cover (by yourself and with backup), then notify your patients of this. Then assist them in obtaining that level of care, as it is often required in the advanced stages of the illness.

4. What else would you specifically discuss?

As above. In addition, the following phrases may be useful:

- "What concerns you most about your illness?"
- "As you think about your illness, what is the best and worst that might happen to you?"
- "What has been most difficult for you about this illness?"
- "What are your hopes (your expectations, your fears) for the future?"
- "As you think about the future, what is most important to you? What matters the most to you?"

Lo, B., Quill, T., and Tulsky, J. *Discussing Palliative Care with Patients.* American College of Physicians.

Print

Return to Page 1

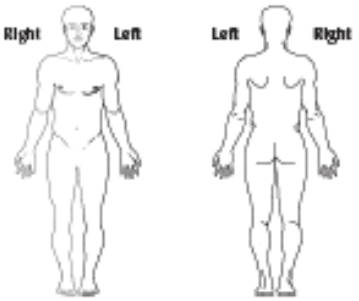
CANADIAN Virtual Hospice

SYMPTOM DIARY

no symptom

worst possible symptom

This diary can be used to record your symptoms, when they occur and what you did to treat them. It can be taken to your health care appointments to help explain the symptoms you are experiencing. If your symptoms are not relieved by your treatment, call your health care provider.



Use this diagram to show the location of your pain

Date and Time	**What is your symptom?** *Name the symptom and location. Describe the symptom and use the number scale above*	**What were you doing when the symptom started or got worse?**	**Did you take medication or try other treatments?** *If so, what, and how much?*	**How did they work?** *Rate the symptom, describe it and use the number scale above*	**Other comments, issues or side effects?**

Reviewed April 2009

Adapted from: AGS Panel on Persistent Pain in Older Person. American Geriatrics Society. J Am Geriatr Society 2002; 50: June suppl

Print

Return to Page 1

BRITISH COLUMBIA MEDICAL ASSOCIATION | Guidelines & Protocols Advisory Committee

SENIORS ASSESSMENT TOOL

This Assessment Tool pertains to the Guideline:

Link to Frail Elderly Guidelines

BRITISH COLUMBIA The Best Place on Earth | Ministry of Health Services

NAME OF SENIOR	PERSONAL HEALTH NUMBER	DATE

NAME OF PHARMACY	LOCATION

1. How has your health been since your last visit? ❑ better ❑ same ❑ worse: _____

2. Do you have concerns or problems with any of the following:

Medications	❑ No	❑ Yes: _____
Pain	❑ No	❑ Yes: _____
Falls	❑ No	❑ Yes: _____
Decreased energy	❑ No	❑ Yes: _____
Nutrition	❑ No	❑ Yes: _____
Memory	❑ No	❑ Yes: _____
Bladder/Bowels	❑ No	❑ Yes: _____
Hearing	❑ No	❑ Yes: _____
Vision	❑ No	❑ Yes: _____
Sleep	❑ No	❑ Yes: _____
Depression/Lonliness	❑ No	❑ Yes: _____
Looking after yourself	❑ No	❑ Yes: _____
Looking after your home	❑ No	❑ Yes: _____
Finances	❑ No	❑ Yes: _____
Transport	❑ No	❑ Yes: _____

3. Where do you live? ❑ own home ❑ with family ❑ facility
   ❑ other: _____
4. Do you live alone? ❑ No ❑ Yes
5. Do you have help in the home? ❑ No ❑ Yes:
6. Do you have a contact for emergencies? ❑ No ❑ Yes
   If yes, who could you call? ❑ family friend ❑ neighbour ❑ Lifeline
   ❑ other: _____
7. Have you signed a Power of Attorney? ❑ No ❑ Yes
8. Have you made a Will? ❑ No ❑ Yes
9. Do you want to discuss end-of-life plans? ❑ No ❑ Yes
10. Have you signed a "No CPR" form? ❑ No ❑ Yes
11. Would you consider Lifeline quick response? ❑ No ❑ Yes ❑ I have Lifeline (or similar service)

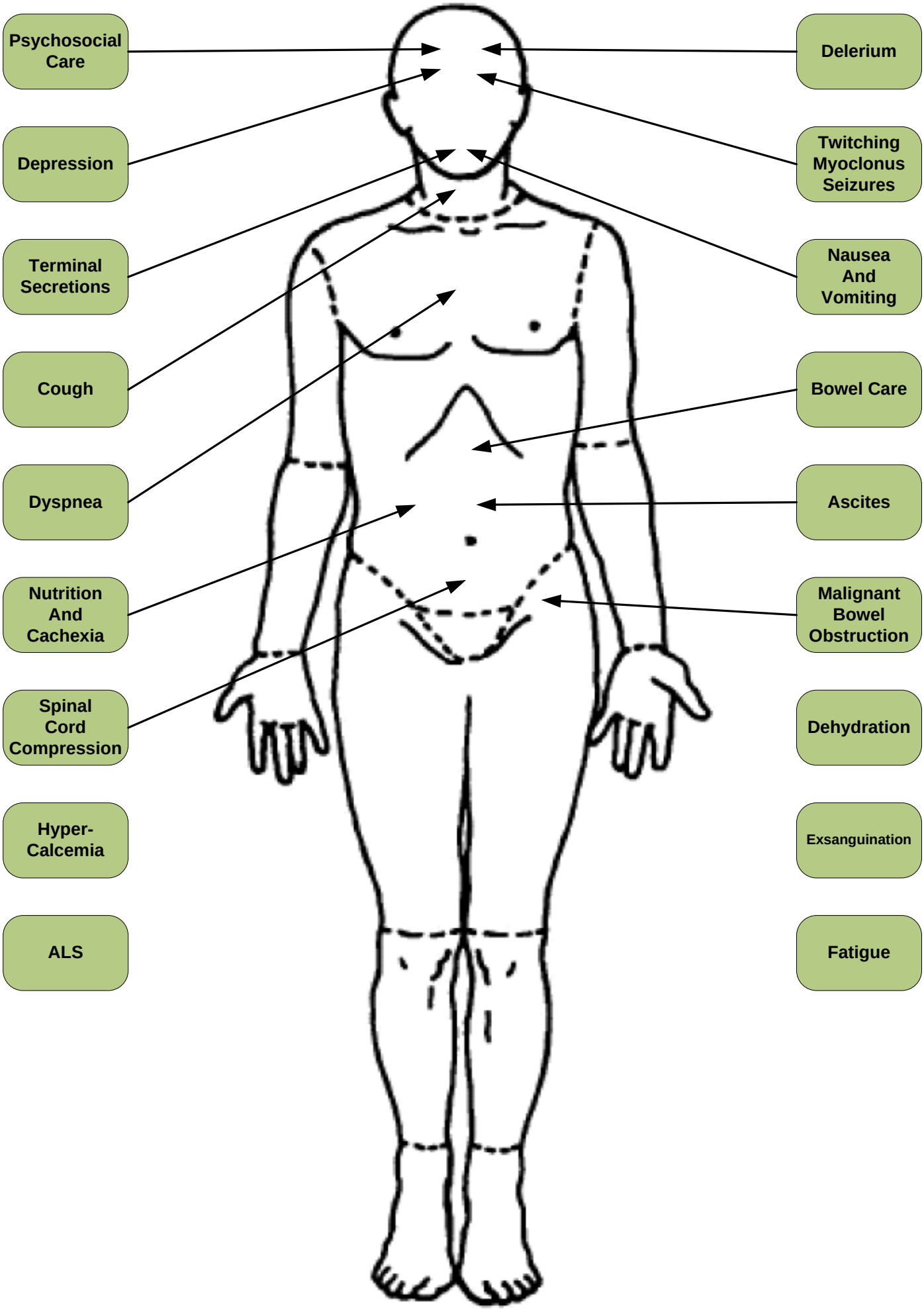
The Seniors Assessment Tool was developed as part of the Seniors-at-Risk Initiative (Trail, B.C.)

Return to Page 1

GPAC Part II – Pain and Symptom

Being developed

Return to Page 1



THE SIX STEPS OF SPIKES

STEP 1: S—SETTING UP the Interview

Mental rehearsal is a useful way for preparing for stressful tasks. This can be accomplished by reviewing the plan for telling the patient and how one will respond to patients' emotional reactions or difficult questions. As the messenger of bad news, one should expect to have negative feelings and to feel frustration or responsibility. It is helpful to be reminded that, although bad news may be very sad for the patients, the information may be important in allowing them to plan for the future.

Sometimes the physical setting causes interviews about sensitive topics to flounder. Unless there is a semblance of privacy and the setting is conducive to undistracted and focused discussion, the goals of the interview may not be met. Some helpful guidelines:

- *Arrange for some privacy*. An interview room is ideal, but, if one is not available, draw the curtains around the patient's bed. Have tissues ready in case the patient becomes upset.
- *Involve significant others*. Most patients want to have someone else with them but this should be the patient's choice. When there are many family members, ask the patient to choose one or two family representatives.
- *Sit down*. Sitting down relaxes the patient and is also a sign that you will not rush. When you sit, try not to have barriers between you and the patient. If you have recently examined the patient, allow them to dress before the discussion.
- *Make connection with the patient*. Maintaining eye contact may be uncomfortable but it is an important way of establishing rapport. Touching the patient on the arm or holding a hand (if the patient is comfortable with this) is another way to accomplish this.
- *Manage time constraints and interruptions*. Inform the patient of any time constraints you may have or interruptions you expect. Set your pager on silent or ask a colleague to respond to your pages.

STEP 2: P—ASSESSING THE PATIENT'S PERCEPTION

Steps 2 and 3 of SPIKES are points in the interview where you implement the axiom "before you tell, ask." That is, before discussing the medical findings, the clinician uses open-ended questions to create a reasonably accurate picture of how the patient perceives the medical situation—what it is and whether it is serious or not. For example, "What have you been told about your medical situation so far?" or "What is your understanding of the reasons we did the MRI?" Based on this information you can correct misinformation and tailor the bad news to what the patient understands. It can also accomplish the important task of determining if the patient is engaging in any variation of illness denial: wishful thinking, omission of essential but unfavorable medical details of the illness, or unrealistic expectations of treatment.

STEP 3: I—OBTAINING THE PATIENT'S INVITATION

While a majority of patients express a desire for full information about their diagnosis, prognosis, and details of their illness, some patients do not. When a clinician hears a patient express explicitly a desire for information, it may lessen the anxiety associated with divulging the bad news. However, shunning information is a valid psychological coping mechanism and may be more likely to be manifested as the illness becomes more severe. Discussing information disclosure at the time of ordering tests can cue the physician to plan the next discussion with the

patient. Examples of questions asked the patient would be, "How would you like me to give the information about the test results? Would you like me to give you all the information or sketch out the results and spend more time discussing the treatment plan?". If patients do not want to know details, offer to answer any questions they may have in the future or to talk to a relative or friend.

STEP 4: K—GIVING KNOWLEDGE AND INFORMATION TO THE PATIENT

Warning the patient that bad news is coming may lessen the shock that can follow the disclosure of bad news and may facilitate information processing. Examples of phrases that can be used include, "Unfortunately I've got some bad news to tell you" or "I'm sorry to tell you that..."
Giving medical facts, the one-way part of the physician-patient dialogue, may be improved by a few simple guidelines. First, start at the level of comprehension and vocabulary of the patient. Second, try to use nontechnical words such as "spread" instead of "metastasized" and "sample of tissue" instead of "biopsy." Third, avoid excessive bluntness (e.g., "You have very bad cancer and unless you get treatment immediately you are going to die.") as it is likely to leave the patient isolated and later angry, with a tendency to blame the messenger of the bad news. Fourth, give information in small chunks and check periodically as to the patient's understanding. Fifth, when the prognosis is poor, avoid using phrases such as "There is nothing more we can do for you." This attitude is inconsistent with the fact that patients often have other important therapeutic goals such as good pain control and symptom relief.

STEP 5: E—ADDRESSING THE PATIENT'S EMOTIONS WITH EMPATHIC RESPONSES

Responding to the patient's emotions is one of the most difficult challenges of breaking bad news. Patients' emotional reactions may vary from silence to disbelief, crying, denial, or anger.
When patients get bad news their emotional reaction is often an expression of shock, isolation, and grief. In this situation the physician can offer support and solidarity to the patient by making an empathic response. An empathic response consists of four steps:

- First, observe for any emotion on the part of the patient. This may be tearfulness, a look of sadness, silence, or shock.
- Second, identify the emotion experienced by the patient by naming it to oneself. If a patient appears sad but is silent, use open questions to query the patient as to what they are thinking or feeling.
- Third, identify the reason for the emotion. This is usually connected to the bad news. However, if you are not sure, again, ask the patient.
- Fourth, after you have given the patient a brief period of time to express his or her feelings, let the patient know that you have connected the emotion with the reason for the emotion by making a connecting statement. An example:
  Doctor: I'm sorry to say that the x-ray shows that the chemotherapy doesn't seem to be working [pause]. Unfortunately, the tumor has grown somewhat.
  Patient: I've been afraid of this! [Cries]
  Doctor: [Moves his chair closer, offers the patient a tissue, and pauses.] I know that this isn't what you wanted to hear. I wish the news were better.

In the above dialogue, the physician observed the patient crying and realized that the patient was tearful because of the bad news. He moved closer to the patient. At this point he might have also touched the patient's arm or hand if they were both comfortable and paused a moment to allow her to get her composure. He let the patient know that he understood why she was upset by making a statement that reflected his understanding. Other examples of empathic responses can be seen in Table 2✦.

Next -->

Table 2. Examples of empathic, exploratory, and validating responses

Empathic statements	Exploratory questions	Validating responses
"I can see how upsetting this is to you."	"How do you mean?"	"I can understand how you felt that way."
"I can tell you weren't expecting to hear this."	"Tell me more about it."	"I guess anyone might have that same reaction."
"I know this is not good news for you."	"Could you explain what you mean?"	"You were perfectly correct to think that way."
"I'm sorry to have to tell you this."	"You said it frightened you?"	"Yes, your understanding of the reason for the tests is very good."
"This is very difficult for me also."	"Could you tell me what you're worried about?"	"It appears that you've thought things through very well."
"I was also hoping for a better result."	"Now, you said you were concerned about your children. Tell me more."	"Many other patients have had a similar experience."

Until an emotion is cleared, it will be difficult to go on to discuss other issues. If the emotion does not diminish shortly, it is helpful to continue to make empathic responses until the patient becomes calm. Clinicians can also use empathic responses to acknowledge their own sadness or other emotions ("I also wish the news were better"). It can be a show of support to follow the empathic response with a validating statement, which lets the patient know that their feelings are legitimate.

Again, when emotions are not clearly expressed, such as when the patient is silent, the physician should ask an exploratory question before he makes an empathic response. When emotions are subtle or indirectly expressed or disguised as in thinly veiled disappointment or anger ("I guess this means I'll have to suffer through chemotherapy again") you can still use an empathic response ("I can see that this is upsetting news for you"). Patients regard their oncologist as one of their most important sources of psychological support, and combining empathic, exploratory, and validating statements is one of the most powerful ways of providing that support (Table 2✦). It reduces the patient's isolation, expresses solidarity, and validates the patient's feelings or thoughts as normal and to be expected.

Next -->

Return to Page 1

STEP 6: S—STRATEGY AND SUMMARY

Patients who have a clear plan for the future are less likely to feel anxious and uncertain. Before discussing a treatment plan, it is important to ask patients if they are ready at that time for such a discussion. Presenting treatment options to patients when they are available is not only a legal mandate in some cases, but it will establish the perception that the physician regards their wishes as important. Sharing responsibility for decision-making with the patient may also reduce any sense of failure on the part of the physician when treatment is not successful. Checking the patient's misunderstanding of the discussion can prevent the documented tendency of patients to overestimate the efficacy or misunderstand the purpose of treatment.

Clinicians are often very uncomfortable when they must discuss prognosis and treatment options with the patient, if the information is unfavorable. Based on our own observations and those of others, we believe that the discomfort is based on a number of concerns that physicians experience. These include uncertainty about the patient's expectations, fear of destroying the patient's hope, fear of their own inadequacy in the face of uncontrollable disease, not feeling prepared to manage the patient's anticipated emotional reactions, and sometimes embarrassment at having previously painted too optimistic a picture for the patient.

These difficult discussions can be greatly facilitated by using several strategies. First, many patients already have some idea of the seriousness of their illness and of the limitations of treatment but are afraid to bring it up or ask about outcomes. Exploring the patient's knowledge, expectations, and hopes (step 2 of SPIKES) will allow the physician to understand where the patient is and to start the discussion from that point. When patients have unrealistic expectations (e.g., "They told me that you work miracles."), asking the patient to describe the history of the illness will usually reveal fears, concerns, and emotions that lie behind the expectation. Patients may see cure as a global solution to several different problems that are significant for them. These may include loss of a job, inability to care for the family, pain and suffering, hardship on others, or impaired mobility. Expressing these fears and concerns will often allow the patient to acknowledge the seriousness of their condition. If patients become emotionally upset in discussing their concerns, it would be appropriate to use the strategies outlined in step 5 of SPIKES. Second, understanding the important specific goals that many patients have, such as symptom control, and making sure that they receive the best possible treatment and continuity of care will allow the physician to frame hope in terms of what it is possible to accomplish. This can be very reassuring to patients

.

SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer
Walter F. Baile[a], Robert Buckman[b], Renato Lenzi[a], Gary Glober[a], Estela A. Beale[a], Andrzej P. Kudelka[b]
[a] The University of Texas MD Anderson Cancer Center, Houston, Texas, USA; [b] The Toronto-Sunnybrook Regional Cancer Centre, Toronto, Ontario, Canada

Practice Support Program...an initiative of the General Practice Services Committee

Scripted Questions for Advance Care Planning

1. What do you think is the cause of your health condition/symptoms?

2. How much intervention do you want? (i.e., No assisted ventilation? BIPAP? Better symptom control?)

3. What do you hope for with this current plan of care? What else do you hope for?

4. What fears or worries do you have about your illness or medical care?

5. What was your last hospitalization like? What did it mean to you?

6. Have you talked with your family about your wishes for future medical care?

7. If you weren't able to make your own health care decisions, who would make them for you?

8. How comfortable are you talking with your family/friends about these wishes?

9. You and I have talked about CPR, and I gave you some booklets on it. What have you learned about CPR?

10. What do you understand about your health condition? What does your family understand?

11. What do you know about the possible complications of _____ (kidney failure, COPD, CHF, etc.)?

12. Are there any other concerns you have about your health care wishes?

13. How has your illness interfered with your daily activities?

14. Tell me what you understand about the options for treating your illness.

15. What treatments/medications interfere with your quality of life?

Source: *"Curriculum Package The Palliative Approach to Chronic Disease Management", BC Hospice Palliative Care Association's (BCHPCA) Learning Centre for Palliative Care, BC, July 2009*

Print

Return to Page 1

PSP
A GPSC Initiative

PATIENT NAME	DOB
PHN	OTHER
ADDRESS	

DIAGNOSIS

Main Diagnosis	Date of Diagnosis	Secondary Diagnosis	Date of Diagnosis
	Ht		
	Wt		
		Drug / Environmental Allergies	
Patient Values/Preferences/Key Goals			
Estimated Prognosis		Family/SDM: Values/Preferences/Key concerns	
Preferred Place Of Death			

CONTACTS / CARE TEAM

Primary Health Provider	Phone	Primary Care Giver	
Substitute Decision Maker	Phone	Key Family Members	Phone.
Key Family Members	Phone	Specialists (Oncologist/Palliative/Other)	Phone
Specialists (Oncologist/Palliative/Other)	Phone	Specialists (Oncologist/Palliative/Other)	Phone
Specialists (Oncologist/Palliative/Other)	Phone	Pharmacist	Phone
Home Health	Phone	Community Nurse(s)	Phone
Palliative Care Team	Phone	Home Oxygen	Phone
Support Services (Home Support, Hospice Community)	Phone	Funeral Home	Phone
Other	Phone	Other	Phone

CARE PLANNING DOCUMENTATION

DOCUMENT	COMPLETED	DOCUMENT	COMPLETED
☐ Home Health Referral		☐ Hospice/Palliative Care Registration	
☐ Palliative Care Benefits (Pharmacare) *(HLTH 349)*		☐ Compassionate Care Benefits *(SC INS5216B)*	
☐ My Voice© workbook		☐ Advance Directive/ Greensleeve	
☐ No Cardiopulmonary Resuscitation *(HLTH 302.1)*		☐ Notification of Expected Home Death *(HLTH 3987)*	

Return to Page 1

PSP
A GPSC Initiative

PATIENT NAME	DOB
PHN	OTHER
ADDRESS	

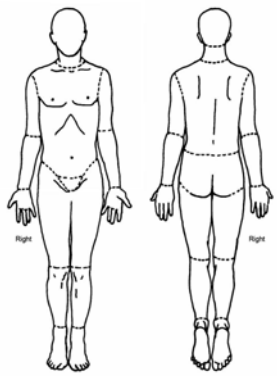
COLLABORATIVE CARE PLANNING

KEY: 1 = Patient 2 = Family Members 3 = Professionals (Please write names

Date	Who was present?	Issues/Outcomes	Followup *(see Key)*

ASSESSMENT

ESAS-r 0-Best10-Worst	ASSESSMENT DATES				ESAS-r 0-Best10-Worst	ASSESSMENT DATES			
LAB Hb					PAIN #1/#2				
GFR					TIREDNESS				
					NAUSEA				
					DEPRESSION				
PPS					ANXIETY				
OTHER					DROWSY				
CONSTIPATION					APPETITE				
QUALITY OF LIFE					WELL-BEING				
					DYSPNEA				



MEDICATION RECORD

MEDICATION	START	DOSE	FREQ	DATE	DATE	DATE	DATE	DATE

Return to Page 1

PSP
A GPSC Initiative

MOA Checklist

CONTACT INFORMATION

Patient Name	DOB	PHN	BCCA #
Address		Family/Representative	
		Primary Phone	Other Phone
		Main Diagnosis	Date
Primary Phone	Other Phone	Secondary Diagnosis	Date

PALLIATIVE CARE / END OF LIFE RELATED FEES

(14063) Palliative Care Planning Fee billed on *(date):*

APPT DATE	BILLING CODE	ENTERED	APPT DATE	BILLING CODE	ENTERED	APPT DATE	BILLING CODE	ENTERED

FREQUENTLY USED BILLING CODES REFER TO *PHYSICIAN BILLING REFERENCE FOR END OF LIFE CARE*

PATIENT IDENTIFICATION TRIGGERS - *A PALLIATIVE APPROACH TO CARE*

- ☐ Surprise question to identify patients "would you be surprised if this patient died in the next year?"
- ☐ Missing appointments or unusual behaviour eg. Change in gait or personal care *(hygiene, dressing etc.)*
- ☐ Repeated hospital or emergency room admissions
- ☐ Poly-pharmacy Issues
- ☐ Admissions to long-term care *("why" are they there, not only that they were admitted)*
- ☐ Changes in ability to care for self
- ☐ Family Members phoning MOA to inquire about patient
- ☐ Changes in communication eg. *Family calling instead of patient*
- ☐ Intuition/Instinct

CARE PLANNING DOCUMENTATION

DOCUMENT	COMPLETED Date	FAXED Date	RECEIVED Date
☐ Home Health Referral			
☐ Palliative Care Benefits (Pharmacare) *(HLTH 349)*			
☐ My Voice© workbook			
☐ No Cardiopulmonary Resuscitation *(HLTH 302.1)*			
☐ Hospice/Palliative Care Registration			
☐ Compassionate Care Benefits *(SC INS5216B)*			
☐ Advance Directive/ Greensleeve			
☐ Notification of Expected Home Death *(HLTH 3987)*			

BRITISH COLUMBIA | Ministry of Health

BC PALLIATIVE CARE BENEFITS REGISTRATION

For – 1. palliative care drug coverage, reassessment or cancellation, and
2. requesting an assessment for medical supplies and equipment

For full information on these benefits, see the Prescriber Guide at www.gov.bc.ca/pharmacare/palliativecareprescriberinfo.

NOTE: FORMS THAT ARE INCOMPLETE, UNSIGNED OR SUBMITTED BY UNAUTHORIZED PERSONS WILL BE RETURNED.
If no medical or nurse practitioner fax number or address is provided, Health Insurance BC (HIBC) will be unable to send a response.

This form is Practitioner-Patient privileged and contains confidential information intended only for the recipient. Any other distribution, copying or disclosure is strictly prohibited. If you have received this form in error, please destroy it and notify the practitioner.

FAXING INSTRUCTIONS: **1.** Fax **ONE** copy of this page to HIBC at 250-405-3587. **2.** Fax **ONE** copy of this page to the local Home and Community Care Office. Contact numbers are available from HealthLink BC (phone 8-1-1), or by visiting http://find.healthlinkbc.ca and, in the Find Services "**What?"** field, entering "home and community care".

☐ **New Patient** ☐ **Reassessment (required after 12 months)** ☐ **Cancellation (patient no longer qualifies) – *complete Step 1 and 4 only***

STEP 1 OF 4: PATIENT'S INFORMATION (please print or type)

Last Name	First Name	Middle Name

Personal Health Number (PHN)	Date of Birth (yyyy / mm / dd)	Gender	Telephone Number (include area code)
		☐ Male ☐ Female	

Mailing Address	City	Province	Postal Code

STEP 2 OF 4: PATIENT'S CONSENT (MANDATORY) - *SIGNATURE IS REQUIRED IN OPTION 1 **OR** 2*

Option 1: Patient's Signature *(a signature is required here **OR** in Option 2 below)*

I consent to registering for drug coverage and an assessment of medical equipment and supply needs.

Signature of Patient	Date Signed (yyyy / mm / dd)

Click anywhere on this form to access form online

OR

Option 2: Signature of Substitute Decision Maker - Legal Representative or Practitioner *(a signature is required here **OR** in Option 1 above)*

If the patient is unable or unavailable to sign the above section (Option 1)

Signature of Legal Representative or Practitioner	Date Signed (yyyy / mm / dd)	Telephone Phone Number (include area code)	
Last Name (print or type)	**First Name (print or type)**	**Initial**	**Relationship to Patient**

STEP 3 OF 4: CERTIFICATION BY MEDICAL OR NURSE PRACTITIONER - MUST BE COMPLETED BY PRACTITIONER (MANDATORY)

Primary Diagnosis	Other Diagnosis

☐ I certify this patient meets all four eligibility criteria as defined below (**all four criteria must be met**):

- is diagnosed with a life-threatening illness or condition
- has a life expectancy of up to 6 months
- wishes to receive palliative care at home (home as defined on page 1)
- consents to the focus of care being primarily palliative rather than treatment aimed at a cure

Supporting Assessment Using SPICT Tool on page 2 **(required)**

List at least 2 General Indicators (for example, 1.a., 1.d.):	List at least 1 Clinical Indicator (for example, 2.d.(1)):

STEP 4 OF 4: SIGNATURE OF MEDICAL OR NURSE PRACTITIONER (MANDATORY)

Name and Mailing Address	**Signature** of Medical or Nurse Practitioner to certify eligiblity and to request coverage	
	Date of Registration (yyyy / mm / dd)	Practitioner College ID Number
	Practitioner Tel Number (with area code)	Practitioner Fax Number

Personal information on this form is collected under the authority of section 22 of the *Pharmaceutical Services Act* for the operations of the BC Palliative Care Benefits Program, Ministry of Health. The personal information will be used to support the applicant to be a beneficiary of the Program. Personal information will be released to PharmaCare for the provision of drug benefits and, where necessary, to the local Home and Community Care office for the determination of medical supplies and equipment needs. If you have any questions about the collection of personal information on this form, contact Health Insurance BC (HIBC) from Vancouver at 604 683-7151 or, from elsewhere in BC, toll-free at 1 800 663-7100. This information will be used and disclosed in accordance with the *Freedom of Information and Protection of Privacy Act* and the *Pharmaceutical Services Act*.

Next -->

BRITISH COLUMBIA | Ministry of Health

BC PALLIATIVE CARE BENEFITS REGISTRATION

For palliative care drug coverage and requesting an assessment for medical supplies and equipment

BC Palliative Care Benefits support individuals of any age at the end stage of a life-threatening disease or illness who wish to receive palliative care at home.

Note: Submit ONLY page 3 of this form. Please do not submit duplicate registration forms.

Not sure if your patient is already registered? Contact the Palliative Care confirmation line at Health Insurance BC (HIBC) at 250-405-3612.

You will need: medical or nurse practitioner license number and the patient's PHN, date of birth, primary diagnosis, and address.

HOW TO REGISTER YOUR PATIENT FOR BC PALLIATIVE CARE BENEFITS:

MEDICAL OR NURSE PRACTITIONER

1. Confirm your patient's eligibility - see "Who is eligible" below (also refer to the SPICT tool on page 2 to support assessment).
2. Have an "advance care plan conversation" with the patient and/or legal representative. (See "My Voice" under **Links** below)
3. Complete all sections of page 3 of this form, and ensure there are two signatures on the form (one in Step 2 - Patient's Consent and one in Step 4 - Medical or Nurse Practitioner Certification).
4. Provide your patient with the Patient Information Sheet (see **Links** below)
5. Fax the form to TWO locations: one copy to HIBC; one copy to the local Home and Community Care office (see Faxing Instructions on page 3).
6. If patient is still receiving benefits after 1 year, re-assess your patient's eligibility.

PATIENT

1. Receives a copy of the Patient Information sheet.
2. Receives coverage of drugs within 24 hours of receipt of form by HIBC.
3. Is contacted by local health authority to schedule assessment of their requirements for medical supplies and equipment.

BC PALLIATIVE CARE BENEFITS INFORMATION:

Who is eligible? Any BC resident who:
- is diagnosed with a life-threatening illness or condition, and
- has a life expectancy of up to 6 months, and
- wishes to receive palliative care at home**; and,
- consents to the focus of care being primarily palliative rather than treatment aimed at a cure.

*** For the purposes of this program, "home" means wherever the person is living, whether in their own home, with family or friends, or in a supportive/assisted living residence, or in a hospice unit of a residential care facility (e.g., a community hospice bed that is not covered under PharmaCare Plan B). Your care facility can advise you whether you are covered by PharmaCare Plan B.*

What will be covered?

BC Palliative Care Drug Plan

PharmaCare covers 100% of the eligible cost of prescriptions (including selected over-the-counter medications) listed in the Plan P formulary.

Practitioners must prescribe the over-the-counter medications in the formulary for the patient to receive coverage. Medications not included in the formulary may be covered under the patient's usual PharmaCare plan (e.g., Fair PharmaCare).

Please note: "Eligible costs" include the cost of the drug (up to a maximum recognized by PharmaCare) and the dispensing fee (up to a maximum recognized by PharmaCare). If a pharmacy charges more than the PharmaCare maximum price or dispensing fee, the patient may still be required to pay for a portion of the cost.

Medical Supplies and Equipment through the local health authority

A health professional from the local Home and Community Care office will contact the patient to assess their need for palliative supplies and equipment. The patient's needs will be reassessed as required. For a list of approved supplies and equipment, see **Links** below.

When will coverage begin?

Drug coverage begins as soon as HIBC processes the registration (normally within 24 hours). Coverage of medical supplies and equipment begins after the patient's needs have been assessed by the home and community care staff of the local health authority.

Need more information?

- For BC Palliative Care Drug Plan, contact Health Insurance BC (HIBC): Vancouver/Lower Mainland: (604) 683-7151, elsewhere in BC toll-free: 1-800-663-7100.
- For palliative medical supplies and equipment, contact your local Home and Community Care office. Contact information available from HealthLink BC (phone 8-1-1) or at http://find.healthlinkbc.ca

LINKS

My Voice Advance Care Planning Guide: www.gov.bc.ca/home-community-care/advancecareplanningguide
Patient Information Sheet: www.gov.bc.ca/pharmacare/palliativecarebenefitspatientinfo.pdf
Plan P Formulary: www.gov.bc.ca/pharmacare/palliativecareformulary.pdf
Approved Supplies and Equipment: www.gov.bc.ca/home-community-care/policymanual

Next -->

BC PALLIATIVE CARE BENEFITS REGISTRATION
SPICT™ TOOL INDICATORS

Please use the numbered indicators below, based on the Supportive and Palliative Indicators Tool (SPICT TM), to support your assessment (Step 3, last two fields). To see the source document, go to http://www2.gov.bc.ca/assets/gov/health/forms/349_spict_tool.pdf

1. GENERAL INDICATORS OF DETERIORATING HEALTH

1.a. Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
1.b. Dependent on others for most care needs due to physical and/or mental health problems.
1.c. Two or more unplanned hospital admissions in the past 6 months.
1.d. Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
1.e. Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
1.f. Patient asks for supportive and palliative care, or treatment withdrawal.

2. CLINICAL INDICATORS OF ONE OR MORE ADVANCED CONDITIONS

2.a. Cancer

2.a.(1) Functional ability deteriorating due to progressive metastatic cancer.
2.a.(2) Too frail for oncology treatment or treatment is for symptom control.

2.b. Dementia/ Frailty

2.b.(1) Unable to dress, walk or eat without help.
2.b.(2) Eating and drinking less; swallowing difficulties.
2.b.(3) Urinary and faecal incontinence.
2.b.(4) No longer able to communicate using verbal language; little social interaction.
2.b.(5) Fractured femur; multiple falls.
2.b.(6) Recurrent febrile episodes or infections; aspiration pneumonia.

2.c. Neurological disease

2.c.(1) Progressive deterioration in physical and/or cognitive function despite optimal therapy.
2.c.(2) Speech problems with increasing difficulty communicating and/or progressive swallowing difficulties.
2.c.(3) Recurrent aspiration pneumonia; breathless or respiratory failure.

2.d. Heart / Vascular Disease

2.d.(1) NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:
- breathlessness or chest pain at rest or on minimal exertion.

2.d.(2) Severe, inoperable peripheral vascular disease.

2.e. Respiratory Disease

2.e.(1) Severe chronic lung disease with:
- breathlessness at rest or on minimal exertion between exacerbations.

2.e.(2) Needs long term oxygen therapy.
2.e.(3) Has needed ventilation for respiratory failure or ventilation is contraindicated.

2.f. Kidney Disease

2.f.(1) Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
2.f.(2) Kidney failure complicating other life limiting conditions or treatments.
2.f.(3) Stopping dialysis.

2.g. Liver Disease

2.g.(1) Advanced cirrhosis with one or more complications in past year:
- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

2.g.(2) Liver transplant is contraindicated.

Next -->

WHAT ARE BC PALLIATIVE CARE BENEFITS?

BC Palliative Care Benefits support individuals of any age who have reached the end stage of a life-threatening disease or illness and who want to receive medically appropriate palliative care at home.

B.C. residents who are eligible to receive palliative care services at home can:

- receive PharmaCare assistance with the cost of **palliative medications**—through PharmaCare Palliative Care Drug Plan (Plan P)
- access certain **palliative medical supplies and equipment**—through the local health authority

UPDATED! ELIGIBILITY

The individual's **physician** or **nurse practitioner** determines the patient's medical eligibility for palliative care benefits.

BC Palliative Care Benefits are available to all B.C. residents with active MSP coverage[1] who:

- are living at home[2], and
- have been diagnosed with a life-threatening illness or condition, and
- have a life expectancy of up to six months, and
- consent to the focus of care being palliative rather than treatment aimed at cure.

For guidance in determining a patient's medical eligibility, please refer to the Supportive and Palliative Care Indicators Tool (SPICT™) on page 2 of the BC Palliative Care Benefits Registration form at www2.gov.bc.ca/assets/gov/health/forms/349fil.pdf.

BENEFITS

BC PALLIATIVE CARE DRUG PLAN (PLAN P)

The BC Palliative Care Drug Plan (Plan P) covers 100% of the eligible costs of the prescription drugs and selected over-the-counter (OTC) drugs needed for care and treatment at home.

Medications covered by the plan include:

- prescription medications prescribed for pain, symptom control and improved quality of life; and,
- certain OTC drugs required to supplement the prescription drugs and considered to be medically necessary for palliative care.

---

[1] In some instances, PharmaCare may consider extending interim coverage to Canadian citizens/permanent residents who are new B.C. residents and do not yet have Medical Services Plan coverage.

[2] For the purposes of BC Palliative Care Benefits, "home" is defined as wherever the patient is living, whether in their own home or with family or friends, in a supportive or assisted living residence, or in a hospice unit of a residential care facility (i.e., a community hospice bed that is not covered under PharmaCare Plan B).

Medications covered are listed in the BC Palliative Care Drug Plan formulary available at www.gov.bc.ca/pharmacare/palliativecareformulary.pdf.

Plan P does not cover items **not** listed in the plan formulary such as vitamins, herbs, nutritional supplements or medical marijuana.

Note: Needles and syringes for administration of injectable medications are provided by the health authorities as medical supplies and equipment benefits.

Once a patient's registration is processed, they can fill an eligible prescription at any pharmacy in British Columbia.

Benefits under the BC Palliative Care Drug Plan continue for as long as the person meets the eligibility criteria. However, reassessment of the patient's eligibility is required at 12 months (refer to *Reassessment/Cancellation* on page 6).

BC PALLIATIVE CARE DRUG PLAN FORMULARY

The drug formulary defines which prescription and OTC drugs are covered under this plan.

The plan provides patients receiving palliative care at home with access to the same palliative drugs they would receive at no charge if they were in hospital.

BC Palliative Care Drug Plan medications are selected for the formulary based on the following criteria:

- the prescription or OTC medication is prescribed for pain and symptom control; and,
- the prescription or OTC medication is prescribed to improve quality of life for palliative patients; and,
- providing the drug to palliative patients supports and enables patients to remain at home.

To receive coverage of the OTC drugs in the Plan P formulary, a patient must present a prescription for the medication at their pharmacy. This allows the pharmacy to enter the medication in the PharmaNet system, which enables PharmaCare to cover the eligible costs.

Drugs not included in the Palliative Care Drug Plan formulary may be covered under the patient's usual PharmaCare plan (e.g., Fair PharmaCare or, for recipients of B.C. Income Assistance, Plan C).

The most recent version of the formulary is on the PharmaCare website at www.gov.bc.ca/pharmacare/palliativecareformulary.pdf.

PAYMENT OF DRUG COST

When presented with a prescription for a drug or OTC medication for an individual registered for the BC Palliative Care Drug Plan, the pharmacy enters a claim for the prescription on PharmaNet. PharmaCare then pays the pharmacy directly for:

- drug costs up to the PharmaCare maximum price, and
- a dispensing fee (up to the maximum allowable dispensing fee).

PLAN P COVERAGE FOR NEW B.C. RESIDENTS

BC Palliative Care Drug Plan coverage is available to new B.C. residents who have not yet qualified for the B.C. Medical Services Plan (MSP).

Patients do not need active MSP coverage but **do** require a B.C. Personal Health Number (PHN). A PHN can be assigned at any B.C. community pharmacy.

Because PharmaCare's claim system, PharmaNet, cannot process claims for Plan P patients who are not enrolled in MSP, Plan P patients without MSP must pay for their prescribed palliative medications and then submit the receipts to PharmaCare for reimbursement.

To request Plan P coverage for a new B.C. resident who does not have MSP coverage, use the usual registration process:

- Ask the patient for their B.C. PHN.
- Submit a BC Palliative Care Benefits Registration form (HLTH 349) to
  - PharmaCare at the fax number provided at the bottom of the form, and
  - your local Home and Community Care Office (who will contact the patient to assess their need for palliative supplies and equipment).
- When PharmaCare has processed the registration it will notify you and provide a Confirmation of Coverage letter for your patient. The Confirmation of Coverage letter explains to the patient that they should obtain MSP coverage as soon as they qualify and that, once their MSP coverage begins, PharmaCare will pay its portion of any eligible prescription claim directly to the pharmacy at the time of purchase.

WHEN PATIENTS DO NOT MEET THE ELIGIBILITY CRITERIA

If a patient does not meet the criteria for the BC Palliative Care Drug Plan (Plan P), consider coverage options through other government insurers (such as Veterans Affairs Canada) and private insurers.

Please note that individuals covered by Health Canada's Non-Insured Health Benefits (NIHB) or Veterans Affairs Canada (VAC) require coverage under the BC Palliative Care Drug Plan *only if a medication is not covered by NIHB or VAC*.

Members of the Canadian Forces receive coverage through their employer and are, therefore, not eligible for this drug plan.

Patients should register for BC's Fair PharmaCare plan at www..gov.bc.ca/fairpharmacareregistration if they have not already done so. Fair PharmaCare covers PharmaCare benefits not included in Plan P.

SPECIAL AUTHORITY COVERAGE FOR DRUGS NOT INCLUDED IN THE PLAN FORMULARY

Most drugs in the BC Palliative Care Drug Plan (Plan P) formulary are regular PharmaCare benefits (that is, they are fully covered up to a maximum drug cost for each drug that PharmaCare accepts and up to the maximum dispensing fee). Drugs **not** included in the Plan P formulary may be covered under another PharmaCare plan (e.g., Fair PharmaCare). However, sometimes a drug that is not included in the

formulary is needed to alleviate patient discomfort. If there is no substitute for that drug in the formulary, PharmaCare will consider a request for Special Authority Plan P coverage.

To request Plan P coverage of a medication not included in the formulary:

- Fax to PharmaCare a completed General Special Authority Request Form (HLTH 5328).

  The Special Authority fax number can be found on the request form. Faxing is the quickest method.
- Clearly mark "For Palliative Care Registrant" on the request form to ensure it receives priority attention.
- Include adequate documentation with the request.

  A decision on coverage may be delayed if PharmaCare needs to call the physician and/or consultant for additional information.

MEDICAL SUPPLIES AND EQUIPMENT BENEFITS

This component provides individuals who are receiving palliative care at home with access to certain medical supplies and equipment. The Ministry of Health funds health authorities to deliver this component of the BC Palliative Care Benefits.

ELIGIBILITY

Health Authorities provide these benefits at no charge to eligible individuals based on need as assessed by the health authority's designated health professional(s). Coverage includes access to certain medical supplies and equipment that support the delivery of safe palliative care at home.

Eligible patients are those who

- are in the last six months of their lives, and
- may potentially require care in a hospital if their palliative medical supplies and equipment are not provided.

A patient's palliative needs are assessed on an ongoing basis monthly or more frequent basis. If it is determined that a patient no longer needs palliative supplies and equipment, he/she would need to purchase supplies and equipment themselves.

LIST OF MEDICAL SUPPLIES AND EQUIPMENT

A list of medical supplies and equipment provided by the health authorities is included in Appendix A – Medical supplies and equipment.

Health Authorities may provide equipment in a variety of ways, including arrangements by purchase of equipment:

- medical supply companies for lease or rentals
- organizations such as the Canadian Red Cross Health Equipment Loan Program
- for actual purchase of technology such as CAD pumps by a Community Health Services Society with a contract for repair and maintenance with the Community Health Council

HEALTH AUTHORITY CONTACT INFORMATION

Home and Community Care offices of the local health authorities are listed in the blue pages of the telephone directory. Contact information may also be obtained from HealthLink BC (phone 8-1-1 or visit HealthLink BC's search site at http://find.healthlinkbc.ca and, in the search field, enter "home and community care."

ADDITIONAL PATIENT SUPPORT THROUGH HEALTH AUTHORITIES

HOME OXYGEN

Subsidized home oxygen for all eligible patients, including palliative patients, is delivered **through the Home Oxygen Program in each health authority**. Home oxygen is not covered under BC Palliative Care Benefits.

For more information, contact your local health authority's Home Oxygen Program or visit HealthLink BC's website at http://find.healthlinkbc.ca and, in the Find Services **What?** field, enter "home oxygen program."

PALLIATIVE CARE PROGRAMS

The home and community care office of your local health authority can advise your patient of other palliative care programs and supports that are available.

SUBMITTING NEW REGISTRATIONS, RENEWALS OR CANCELLATIONS

OVERVIEW

Submit a registration form to:

1. Register a new patient for benefits
2. Ensure continued benefits for a patient each year after reassessment
3. Discontinue benefits for a patient who no longer requires palliative care

PATIENT SIGNATURE REQUIREMENT

The *Freedom of Information and Protection of Privacy Act* requires that the patient or the patient's legal representative consent to the release of personal information such as basic demographic data and diagnosis. For this reason, the patient or their legal representative must sign the application.

If a patient is unable to sign the form and has no legal representative (or the legal representative cannot be reached), a physician or nurse practitioner may act on behalf of the patient.

In these cases, the physician or nurse practitioner should:

- sign in the **Signature of Applicant** (or legal representative) field, and
- note "Patient's physician/nurse practitioner" in the **Relationship to Applicant** field.

NEW REGISTRATIONS

Once a physician or nurse practitioner has certified that a patient meets the medical criteria, the physician or nurse practitioner completes a BC Palliative Care Benefits Registration form (HLTH 349) and faxes it to both Health Insurance BC (for drug coverage) and the home and community care office of the health authority (to initiate an assessment for palliative medical supplies and equipment).

Complete all fields to ensure coverage is not delayed.

NEW! REASSESSMENT/CANCELLATION

Physcians and nurse practitioners are required to re-assess a patient's eligibility at 12 months.

- If the patient continues to meet the eligibility requirements, at the top of the form, check off "Reassessment." Then complete Steps 1 through 4.
- If the patient does not meet the eligibility criteria, At the top of the form, check off "Cancellation." Then complete Step 1 and Step 4 only.

If you do not submit a reassessment form 12 months after initial registration, the patient's eligibility may be subject to verification for continued benefits.

UPDATED! SUBMITTING THE FORM

To ensure prompt processing, please complete all sections of the form. If the information is not complete, Health Insurance BC and/or the health authority will have to return the form to you to obtain the missing information.

Please fax the form to:

- Health Insurance BC at **250-405-3587**, and
- the appropriate **Home and Community Care office** of the local health authority, as listed in the blue pages of your telephone directory.

> **IMPORTANT**: Please do **not** fax the application to a Health Authority's head office.
>
> To find the contact information for the Home and Community Care office, visit HealthLink BC's search site at http://find.healthlinkbc.ca. In the search field, enter "home and community care."

ORDERING REGISTRATION FORMS

The **registration form**, this **guide**, a **patient information sheet,** and the **plan formulary** are available on the PharmaCare website at www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/pharmacare/prescribers/plan-p-bc-palliative-care-benefits-program.

If you require any printed copies of the form, please contact the Health Insurance BC Coverage Confirmation Line at **250 405 3612**.

WHEN DOES COVERAGE BEGIN?

BC PALLIATIVE CARE DRUG PLAN—Coverage under the BC Palliative Care Drug Plan begins as soon as Health Insurance BC (which delivers operational services for PharmaCare) processes the registration and enters the information in the PharmaNet system. Although most registrations are entered the same day that they are received, please allow up to 24 hours for processing.

MEDICAL SUPPLIES AND EQUIPMENT BENEFITS—Once the health authority receives the registration form, health authority staff contact the individual or their family. Arrangements will be made for a home visit to assess both the person's eligibility and equipment/supplies needs. Once the patient's care plan and needs are confirmed, health authority staff will arrange for the provision of the approved palliative medical supplies and equipment.

NEW! BC PALLIATIVE CARE BENEFITS—COVERAGE CONFIRMATION LINE

To confirm registration in the BC Palliative Care Drug Plan, the physician or nurse practitioner can phone the Palliative Care Confirmation Line at Health Insurance BC (HIBC) at **250 405 3612**. The line is available 24 hours a day, 365 days a year.

To confirm a patient's registration, you will require the:

- Patient's PHN
- Patient's date of birth
- Patient's address
- Patient's primary diagnosis
- Physician or Nurse Practitioner's license number

PALLIATIVE CARE RESOURCES

HEALTH AUTHORITY HOSPICE PALLIATIVE CARE PROGRAMS

Consultation is available through the Health Authority Hospice Palliative care Programs for physicians and professional care providers.

PROVINCIAL PALLIATIVE CARE CONSULTATION LINE

Physicians throughout BC have access to a 24/7 toll-free phone line for palliative care consultation. The phone line is staffed by palliative care physicians who offer timely clinical advice on pain and symptom management, psychosocial issues, or difficult end-of-life decisions making.

For advice or support, call **1-877-711-5757**.

GENERAL INFORMATION FOR PATIENTS AND CAREGIVERS

Patients or caregivers can consult the following:

Return to Page 1

For general information on BC Palliative Care Benefits	Call HealthLink BC (phone 8-1-1), or for information about drug coverage and basic eligibility requirements, visit the Ministry of Health's PharmaCare website at www.gov.bc.ca/pharmacare
For information on medications included in the formulary	Call Health Insurance BC: • From the Lower Mainland, call 604 683-7151. • From elsewhere in B.C., call 1 800-663-7100
For information on medical equipment and supplies	Local health authorities—See Health Authority Contact Information for details.

APPENDIX A - MEDICAL SUPPLIES & EQUIPMENT

Health authority staff assess the patient's initial and ongoing eligibility and specific needs for palliative supplies and equipment and make arrangements for the provision of approved supplies and equipment.

MEDICAL SUPPLIES

Health authorities provide medical supplies to eligible palliative care patients at no charge based on eligibility for BC Palliative Care Benefits and assessed need.

Supplies available to eligible patients include:

Routine dressing supplies

- sterile dressing supplies
- bandages, including elastic and adhesive, and tape
- trays (disposable or re-usable)
- solutions and ointments (unless covered by the Palliative Care Drug Plan component of BC Palliative Care Benefits)

Medication administration supplies

- needles, syringes, swabs

Intravenous therapy and subcutaneous supplies

- hydration solutions: Normal saline, 2/3 & 1/3, D5W
- mini-bags, tubing, cathlons, syringes, needles, heparin locks and caps
- Hypodermoclysis equipment

Urinary catheter care supplies

- urinary catheter equipment including drainage tubing, drainage bags,
- connectors, leg bag drainage set
- catheterization tray
- disposable gloves (non-sterile)

Incontinence supplies

- incontinence briefs and pads
- condom drainage sets
- disposable gloves (non-sterile)

Medical supplies **not** approved under BC Palliative Care Benefits:

- **ongoing diabetic supplies**—Covered by PharmaCare. Coverage is subject to the rules of a patient's primary plan: Fair PharmaCare, Plan C (B.C. Income Assistance) or Plan F (Children in the At-Home-Program)—except blood glucose monitoring strips which are covered by the local health authority.
- **ostomy supplies**—Covered by PharmaCare. Coverage is subject to the rules of a patient's primary plan: Fair PharmaCare, Plan C (B.C. Income Assistance) or Plan F (Children in the At Home Program).
- **wound care ointments** requiring a prescription (see the BC Palliative Care Drug Plan formulary for these items).

EQUIPMENT

Health authorities provide equipment to eligible BC Pallitaive Care Benefits patients based on assessed need. There is no charge to eligible patients.

Equipment may include:

- hypodermoclysis equipment
- computerized ambulatory drug delivery (CADD) pump equipment, including cassettes and other approved pain control delivery technologies
- pressure redistribution mattresses
- mechanical lifts with slings – may include ceiling lifts with installation according to health authority policy
- commodes, transfer boards, bath seats, floor-to-ceiling poles, wheelchair shower chairs
- walkers
- non-motorized wheelchairs
- hospital beds according to health authority policy

Return to Page 1

Palliative Care Drug Plan (Plan P) Formulary
— List of drugs PharmaCare covers

Last Updated: May 11, 2015

Important Notes:

- Pharmacists must submit a claim on PharmaNet at the time of purchase to enable coverage.
- PharmaCare may not cover all available formulations and strengths of the drugs listed below under Plan P.
  - Examples of drug formulation include: tablet, capsule, liquid, and injection.
  - Examples of drug strength include: 5 mg and 10 mg/ml.
- If PharmaCare covers a generic version of a drug, PharmaCare usually covers only part of the cost of the brand product. Some generic products may be only partially covered depending on the price of competing generic products.
- This formulary is intended only as a general guide to the products covered by PharmaCare's Palliative Care Drug Plan (Plan P) and may not reflect recent changes to the formulary.
- PharmaCare formularies are not a replacement for professional medical judgment and advice.

Formulary Index (by treatment category):

Select a link below or scroll to view the formulary.

Questions? Please contact the Health Insurance BC.

Analgesics 2
Anticoagulants and Coagulants 2
Anticonvulsants 2
Antidiarrheals 2
Antiemetics 2
Anti-infectives 3
Antipruritics 3
Antispasmodics 3
Bone Metabolism Regulators 3
Central Nervous System Stimulants 3
Congestive Heart Failure Therapy 3
Diabetic Agents 3
Diuretics 4
H2 Blockers and Proton Pump Inhibitors 4
Hemorrhoid Therapy (Ointment and Suppositories) 4
Laxatives 4
Psychiatric Medication 4
Respiratory System Therapy 5
Steroids 5
Wound care 5
Other 5

Analgesics	
Non-Opioid	
▪ Acetaminophen	
NSAIDs (This category excludes topical NSAIDs)	
▪ Celecoxib	▪ Meloxicam
▪ Diclofenac	▪ Naproxen
▪ Ibuprofen	
Opioids (This category excludes Demerol, Pentazocine, Butorphanol, Anileridine)	
▪ Codeine products including acetaminophen combinations	▪ Morphine
▪ Fentanyl	▪ Oxycodone
▪ Hydromorphone	▪ Sufentanil
▪ Methadone	
Misc Analgesics	
▪ Ketamine	▪ Xylocaine
▪ Mexiletine	
Anticoagulants and Coagulants	
Anticoagulants	
▪ Heparin sodium	▪ Warfarin
Coagulants – Antifibrinolytic Agents	
▪ Tranexamic acid	
Anticonvulsants	
▪ Carbamazepine	▪ Phenytoin
▪ Gabapentin	▪ Valproic acid
▪ Phenobarbital	
Antidiarrheals	
▪ Bismuth subsalicylate	▪ Octreotide – As a last resort only (e.g., currently covered for profuse diarrhea in advanced AIDS not responsive to multiple constipating agents).
▪ Diphenoxylate	
▪ Loperamide	
Antiemetics	
▪ Dexamethasone	▪ Metoclopramide – oral, parenteral
▪ Dimenhydrinate	▪ Octreotide – As a last resort only (e.g., currently covered for uncontrolled vomiting from an irreversible bowel obstruction not responsive to the use of multiple antiemetics).
▪ Domperidone	▪ Prochlorperazine – oral, suppository
▪ Haloperidol	▪ Promethazine

Anti-infectives	
Antifungal (oral/topical/vaginal preparations)	
▪ Clotrimazole	▪ Ketoconazole
▪ Fluconazole	▪ Nystatin
Antimicrobials	
▪ All antimicrobials normally covered by PharmaCare	
Antivirals	
▪ Acyclovir	▪ Famcyclovir
Antipruritics	
▪ Diphenhydramine	▪ Hydroxyzine
Antispasmodics	
▪ Atropine	▪ Hyoscyamine (Levsin)
▪ Baclofen	▪ Opium and Belladonna – suppositories
▪ Benztropine	▪ Oxybutynin
▪ Dantrolene	▪ Phenazopyridine
▪ Dicyclomine (Bentylol)	▪ Scopolamine – oral, parenteral, patch
Bone Metabolism Regulators	
▪ Clodronate	▪ Pamidronate
▪ Denosumab (Xgeva)	▪ Zoledronic acid – Covered if a cost-effective usage. For example, if a patient is at home, has an estimated life span of more than 4 weeks, and hospital day care is not available or the patient would need transportation to get to a hospital. In such a case, the physician could administer zoledronic acid over 10-15 minutes via a butterfly needle in a peripheral vein.
Central Nervous System Stimulants	
▪ Methylphenidate	
Congestive Heart Failure Therapy	
▪ All ACE inhibitors that are normally PharmaCare benefits	▪ Carvedilol
▪ All antianginals that are normally PharmaCare benefits	▪ Digoxin
▪ All beta blockers that are normally PharmaCare benefits	
Diabetic Agents	
▪ Insulin	▪ Metformin
▪ Glyburide	

Diuretics	
▪ Amiloride	▪ Metolazone
▪ Ethacrynic acid	▪ Spironolactone
▪ Furosemide	▪ Triamterene
▪ Hydrochlorothiazide	
H2 Blockers and Proton Pump Inhibitors	
▪ Pantoprazole magnesium	▪ Rabeprazole
▪ Pantoprazole sodium	▪ Ranitidine
Hemorrhoid Therapy (Ointment and Suppositories)	
▪ Anusol®, Anusol HC® or equivalent preparations	▪ Pramoxine with and without hydrocortizone
▪ Framycetin	▪ Zinc sulfate with and without hydrocortizone
Laxatives	
▪ Bisacodyl	▪ Microlax® enema
▪ Cascara	▪ Magnesium citrate
▪ Docusate sodium	▪ Magnesium hydroxide (Milk of Magnesia)
▪ Fleet enema®	▪ Senna
▪ Glycerin	▪ Senna/Docusate combinations
▪ Lactulose	
Psychiatric Medication	
Antidepressants	
▪ Amitriptyline	▪ Imipramine
▪ Buproprion	▪ Mirtazapine
▪ Citalopram	▪ Nortriptyline
▪ Desipramine	▪ Paroxetine
▪ Doxepin	▪ Sertraline
▪ Escitalopram	▪ Trazodone
▪ Fluoxetine	▪ Venlafaxine
▪ Fluvoxamine	▪ Zuclopenthixol
Antipsychotics	
▪ Aripripazole	▪ Methotrimeprazine
▪ Chlorpromazine	▪ Paliperidone
▪ Haloperidol	▪ Risperidone
▪ Loxapine	
Anxiolytics/Hypnotics	
▪ Alprazolam	▪ Lorazepam – oral, sublingual, parenteral
▪ Clonazepam	▪ Midazolam
▪ Diazepam – oral, parenteral	▪ Oxazepam

Next -->

Return to Page 1

Respiratory System Therapy	
Bronchodilators	
▪ Aminophylline tablets	▪ Salbutamol – inhalers and nebules
▪ Ipratropium – inhalers and nebules	▪ Theophylline
Inhaled Corticosteroids	
▪ Beclomethasone	▪ Fluticasone
▪ Budesonide	▪ mometasone furoate (Asmanex™ Twisthaler™)
▪ Ciclesonide	
Antitussives	
▪ Codeine syrup	▪ Hydrocodone-phenyltoloxamine
Steroids	
▪ Dexamethasone	▪ All topical steroids normally covered by PharmaCare
▪ Prednisone	
Wound care	
▪ Fucidin (topical)	▪ Silver sulfadiazine (topical)
▪ Metronidazole (topical)	
Other	
▪ Azeleic acid topical gel	▪ Potassium chloride solution
▪ Digestive enzymes	▪ Simethicone
▪ Glycopyrrolate	

Return to Page 1

H&CC Referral Form

Pending from HA's

BRITISH COLUMBIA | Ministry of Health

BCEHS | BC Emergency Health Services

NO CARDIOPULMONARY RESUSCITATION – MEDICAL ORDER

Capable patients may request that no cardiopulmonary resuscitation be started on their behalf. This should be done after discussions with their doctor or nurse practitioner. "No cardiopulmonary resuscitation" is defined as no cardiopulmonary resuscitation (no CPR) in the event of a respiratory and/or cardiac arrest.

This form is provided to you or your substitute decision maker to acknowledge that you have had a conversation with a physician or nurse practitioner about a No CPR Order, and understand that no CPR will be provided in circumstances where you can no longer make decisions for yourself. It instructs people such as first responders, paramedics and health care providers not to start CPR on your behalf whether you are at home, in the community or in a residential care facility. The personal information collected on this form assists the health professionals noted above to carry out your wishes. If you have any questions about the collection of this information contact **HealthLink BC at 8-1-1** or go to www.gov.bc.ca/expectedhomedeath.

You or someone at your location should have the form available to show to emergency help if they are called to come to your aid. It is desirable that you wear a MedicAlert® or CPR bracelet or necklet to enable quick verification that you have a No CPR Order in place. To obtain a free No CPR bracelet/necklet, please call 1-800-668-1507, or visit the website at www.medicalert.ca/nocpr. If you change your wishes about this matter, then please inform your doctor, nurse practitioner or residential care facility nurse, and MedicAlert and tear up the form.

PATIENT IDENTIFICATION	Patient Last Name	Birthdate (YYYY / MM / DD)
	Patient First and Middle Name(s)	Personal Health Number (PHN)
	Patient Address	Telephone Number

WITNESSED BY THE PATIENT, OR BY THE PATIENT'S SUBSTITUTE DECISION MAKER (SDM) WHEN THE PATIENT IS INCAPABLE

I, _____ *(patient's name or patient's substitute decision maker if patient is incapable)* have had a conversation with the undersigned physician/nurse practitioner about this No CPR Order in the event of cardiac or respiratory arrest. I understand that in the event of a cardiac or respiratory arrest, no cardiopulmonary resuscitation is to be undertaken.

Patient's Signature	Date Signed
Signature of the Patient's Substitute Decision Maker	Date Signed
Relationship of the Patient's Substitute Decision Maker to the Patient *(e.g. representative, committee of person, or temporary substitute decision maker)*	

SECTION TO BE COMPLETED BY PHYSICIAN/NURSE PRACTITIONER

STATUS OF MEDICAL ORDER

☐ Patient (or SDM) agrees and has signed this form

☐ Patient (or SDM) agrees but has declined signing this form

The above identified patient has expressed wishes to not have CPR in the event of cardiac or respiratory arrest. I have discussed the patient's health status, life expectancy, and expressed wishes with the patient/patient's substitute decision maker. Based on this discussion, I order that in the event of a respiratory and/or cardiac arrest no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect until cancelled or repealed.

Date

ATTENDING PHYSICIAN/NURSE PRACTITIONER		ALTERNATE PHYSICIAN/NURSE PRACTITIONER
Name of Attending Physician / Nurse Practitioner		Name (Print)
License Number of Physician / Nurse Practitioner	Phone Number	Phone Number
Address	Signature	

COPY 1 –TO PATIENT; **COPY 2**–TO ATTENDING PHYSICIAN/NURSE PRACTITIONER; **COPY 3**–IF APPLICABLE, TO HOME & COMMUNITY CARE OR RESIDENTIAL CARE FACILITY

Return to Page 1

PATIENT/ FAMILY INSTRUCTIONS

Looking at this form may be one of the most difficult things you have ever done. Many thoughts and emotions may surface. So often people try to ignore their mortality, yet we all know it is one of the facts of life: we all, one day, will die.

This form is a medical order that reflects your wishes about what you would like to have happen in the event you stop breathing or your heart stops beating. Take time to thoughtfully consider your wishes and ask your health care professionals what resuscitation would entail and any risks to quality and/or quantity of life that could accompany resuscitation if you decided to have it.

Whether you live at home or in a residential care facility, your care team will help you and/or your substitute decision maker to make choices and plans for end-of-life-care. If you have a life-limiting illness and are choosing to die at home, you will need to make additional plans. The steps you will need to consider are listed below.

If you are a family member who is asked to consider this document on behalf of your loved one, all of what is said above applies also. This can be a stressful decision. Remember to seek support from trusted family members, friends and/or a spiritual advisor if you have one and your health care team.

IF YOU WANT TO DIE NATURALLY AT HOME, CONSIDER THESE STEPS

INDIVIDUAL / FAMILY

What to Do Ahead of Time

- Discuss the option of an in-home death with your physician/nurse practitioner and community nurse.
- Make a written plan with your physician/nurse practitioner and community nurse so you are clear about what will happen and so family, friends and others may support your decisions and respect your wishes and know what to do at the time of death. You need to write in your plan:
  - who will pronounce death, IF pronouncement is planned. Pronouncement is NOT necessary if a "Notification of Expected Home Death" form has been completed earlier by you and your doctor or nurse practitioner. The form can be found at www.gov.bc.ca/expectedhomedeath.
  - how your physician/nurse practitioner can be reached;
  - what alternate arrangements have been made should your physician/nurse practitioner be unavailable or cannot be reached;
  - which funeral home will be called to transport the deceased.
- Make prearrangements with a funeral home. Such arrangements will normally involve selecting the funeral home and making plans with the funeral director for transportation of the deceased after death and the method of final disposition. For information on funeral homes in your area, you could contact the B.C. Funeral Association at 1-800-665-3899.
- Ensure that a copy of this form is easily available in your home. If you are away from your home for any reason, take the form with you so it's available should it be necessary.

FAMILY / FRIENDS

What to Do at the Time of Death

- DO NOT CALL 911, the ambulance, coroner, police, or fire department. Review your written plan for who to contact at the time of death.
- CALL family, friends, and the spiritual advisor, if any, you would like to have present.
- CALL the physician/nurse practitioner or community nurse to pronounce death IF a "Notification of Planned Home Death" form has NOT been completed, AND/OR pronouncement is planned.
  - If your physician/nurse practitioner or community nurse cannot be reached, CALL the backup physician/nurse practitioner or community nurse if prearranged.
- IF a "Notification of Planned Home Death" form HAS been completed AND is in your home, call the funeral home after one hour or more has passed since your loved one's breathing has stopped.
  - You do NOT need to call a physician/nurse practitioner about completing a Medical Certificate of Death form. The funeral home can contact the physician or nurse practitioner to obtain a signed certificate within 48 hours, because the body cannot be released for burial or cremation without it.

People to Call	Name	Telephone Number
Phys/Nur. Practitioner		
Alternate Practitioner		
Community Nurse		
Funeral Home		
Spiritual Advisor		
Home Support Agency		
Hospice Program		
Family and Friends		

For more information, go to www.gov.bc.ca/expectedhomedeath

There are communities in British Columbia without physicians or nurse practitioners who live in the community and without a funeral home. It is essential that these situations be discussed by the patient and family and physician/nurse practitioner and an appropriate plan suitable for the community be made in advance.

Service Canada

Print

PR

Return to Page 1

Medical Certificate for Employment Insurance Compassionate Care Benefits

The Authorization to Release this medical information is a separate form and will be provided by the individual requesting that you complete this Medical Certificate for Employment Insurance Compassionate Care Benefits. This certificate and the Authorization form must be submitted together when a claim for compassionate care benefits is made.

Employment Insurance Compassionate Care benefits are available to eligible workers to provide care or support to a family member who is gravely ill with a significant risk of death within 26 weeks (patient).

For more information about the Compassionate Care Benefit, go to: Online Compassionate Care Benefits Link

Note: For Employment Insurance benefit purposes, care or support is defined as:

- directly providing or participating in the care of the patient, or
- providing psychological or emotional support for the patient, or
- arranging for the care of the patient by a third party care provider.

Important: A Medical Practitioner (Health Practitioner other than a Medical Doctor) may complete this form when:

- the patient is in a geographical location where treatment by a Medical Doctor is not readily available **AND**
- the Medical Practitioner is designated by a Medical Doctor to provide treatment to the patient.

A. Patient's Name _____ Date of Birth (y-m-d) _____

B. I last examined the patient on _____ (y-m-d) and certify that the following conditions exist:

1. The patient has a serious medical condition **and** a significant risk of death within the next 26 weeks (6 months).

Yes No

2. The patient requires the care or support of one or more family members within this 6 months.

Yes No

C. Compassionate care benefits are payable to eligible family members from the date in **B** above or the week this medical is signed. In some situations, these benefits are being requested for an earlier period of time and may be payable for this period if you certify that the 2 conditions in **B** above applied to your patient for an earlier period of time.

3. Did the two conditions in B above apply to your patient for an earlier period within the past 6 months?

Yes No If yes, please provide the earlier date (y-m-d) _____

D. (If applicable)

In my professional opinion and to the best of my knowledge, the patient identified above is unable to give consent to the release of medical information because of his age, a physical or mental condition. Yes

Signature (Medical Doctor or Practitioner designated by the Doctor) _____ Date (y - m - d) _____

Contact Information

Medical Doctor, or Medical Practitioner (Health Practitioner), designated by the Doctor (identified above)

Name	Specialty	License Number

Apt no or suite no	Number and Street, Concession, Other	City or Town

Province/Territory	Country	Telephone Number with Area Code	Postal Code (if in Canada)

Non-Canadian Doctors or Non-Canadian Medical Practitioners

Please provide the following information:

- the name of the university - the country and the year you obtained your certification
- your hospital or clinic affiliation and your license number

University	Country	Year (y - m - d)

Hospital/Clinic Affiliation	License Number

Service Canada delivers Employment and Social Development Canada programs and services for the Government of Canada

Service Canada

PF

Return to Page 1

Authorization to Release a Medical Certificate

This form is an Authorization for the release of medical information and must be completed and shown to the Medical Doctor or other Medical Practitioner (Health Practitioner) who will complete the Medical Certificate for Employment Insurance Compassionate Care Benefits. This form and the Medical Certificate for Employment Insurance Compassionate Care Benefits must be submitted together when making a claim for Compassionate Care benefits.

The information provided on this form and the Medical Certificate for Employment Insurance Compassionate Care Benefits is collected by Employment and Social Development Canada (ESDC) under the authority of the *Employment Insurance Act* (EI) to determine the eligibility for compassionate care benefits of one or more family members of a seriously ill individual.

Failure to complete this form and the Medical Certificate for Employment Insurance Compassionate Care Benefits **may** result in family members not being entitled to receive compassionate care benefits.

The information may also be used for policy analysis, research and/or evaluation purposes, in which case, various sources of information under the custody and control of ESDC may be linked. In some instances, information may be disclosed without consent according to the *EI Act*.

The personal information collected herein is administered in accordance with the *EI Act* and *Privacy Act* which states that individuals have the right to the protection of and access to their personal information and have the right to request changes to incorrect information. It will be retained for six years after the last administrative action, as described in Personal Information Bank, Insurance Claim File - Local Office, ESDC PPU 150. Instructions for obtaining this information are outlined in the government publication entitled *Info Source*, a copy of which is located at all Service Canada Centres. Info Source is also located at the following web site address: infosource.gc.ca

Note:

- A Medical Doctor or other Medical Practitioner (Health Practitioner) may request a fee to fill out the Medical Certificate for Employment Insurance Compassionate Care Benefits and ESDC does not reimburse such fees.
- A claimant may avoid unnecessary costs by not submitting the Medical Certificate for Employment Insurance Compassionate Care Benefits if one has already been submitted by any family member for the same patient in the last 26 weeks (6 months).

Section 1- PATIENT INFORMATION

If the ill person (patient) is incapable of consenting to the release of medical information, **Sections 1** and **2 must** be completed by the patient's Legally Authorized or Appointed Representative, **and** the Medical Doctor or Practitioner **must** complete **Section D** of the **Medical Certificate for Employment Insurance Compassionate Care Benefits.**

Patient's Family name	All given names	Date of birth (dd-mm-yyyy)

Residential address

Apartment no.	Number and Street, Concession, Other	City or Town

Province/Territory/State/Region/County	Country	Postal Code (if in Canada)

I hereby authorize the release of the information provided in the Medical Certificate for Employment Insurance Compassionate Care Benefits to all family members claiming Employment Insurance (EI) Compassionate Care Benefits, as well as to ESDC.

Signature _____ Date (dd-mm-yyyy) _____

Section 2- PATIENT REPRESENTATIVE

To be completed by patient's legally authorized or appointed representative if, due to illness, Section 1 is ***not*** signed by patient.

Patient's Representative (Print Name)	Relationship to Patient in Kinship or Law	Telephone Number with Area Code

I am legally appointed or authorized to consent to the disclosure of this patient's medical information.

The patient mentioned in Section 1 is at present unable to consent to the release of medical information.

I authorize the release of this medical information for no other purpose than to facilitate the completion of the Medical Certificate for Employment Insurance Compassionate Care Benefits. I have signed both sections 1 and 2 to authorize the release of information on the Medical Certificate for Employment Insurance Compassionate Care Benefits.

Signature _____ Date (dd-mm-yyyy) _____

Service Canada delivers Employment and Social Development Canada programs and services for the Government of Canada

BRITISH COLUMBIA | Ministry of Health

Print

Return to Page 1

NOTIFICATION OF EXPECTED DEATH IN THE HOME

To be completed by the Attending Medical/Nurse Practitioner

ATTENTION: FUNERAL DIRECTOR

NAME OF FUNERAL HOME			
ADDRESS	CITY	PROVINCE	POSTAL CODE

This is being sent to you in anticipation of death at home in the near future. You have been identified as the funeral home of choice. The family has been instructed to call you one hour after death has occurred for transport of the body.

As the attending medical/nurse practitioner, I certify that this person is known to me and that to the best of my knowledge and belief this is a natural and expected death. Upon death I authorize you to transfer the body and to complete the Registration of Death. I, or my designate, will complete the Medical Certificate of Death within 48 hours. This authorization shall be in effect for 3 months from the date signed.

PATIENT'S NAME	GENDER ☐ M ☐ F	DATE OF BIRTH (DD/MM/YYYY)	PERSONAL HEALTH NUMBER
ADDRESS	CITY	PROVINCE	POSTAL CODE
PRECAUTIONS, IF ANY:			

NAME OF ATTENDING MEDICAL / NURSE PRACTITIONER	PRACTITIONER COLLEGE ID NUMBER	PHONE NUMBER
ADDRESS	CITY	PROVINCE / POSTAL CODE
COMMENTS		
SIGNATURE OF ATTENDING MEDICAL / NURSE PRACTITIONER		DATE SIGNED (DD/MM/YYYY)

Click anywhere on this form to access form online

AUTHORIZATION OF DISPOSITION FOR EXPECTED DEATH AT HOME

To be completed by the person authorized to control the disposition for the expected death at home of: _____

I certify that I am legally authorized to make decisions after death has occurred and that the plan for management of expected death at home has been discussed and agreed to. I agree to the transfer of the body from the home without pronouncement of death by a health care professional and that we will follow the plan by noting the time of death and agreeing to wait at least one hour from the time of death to call the funeral home for transfer of the body. I agree to indemnify and hold harmless the Funeral Home, its employees and agents, from any liability for claims, damages, costs and expenses of whatever kind or nature (except any claim arising out of or in connection with the wilful misconduct, malfeasance, or negligence of the Funeral Home, its employees and agents) incurred in connection with or arising from the Funeral Home dealing with the Patient's body on my instructions.

_____
printed name

_____
signature

_____ _____
date signed *contact phone number*

RELATIONSHIP TO DECEASED

from the *Cremation, Interment and Funeral Services Act*, Sec 5 (1)):

Authorization of disposition is in order of priority as set out below.

- ☐ a) personal representative named in the will;
- ☐ b) spouse of deceased;
- ☐ c) adult child of deceased;
- ☐ d) adult grandchild of deceased;
- ☐ e) if deceased a minor, legal guardian of deceased at time of death;
- ☐ f) parent of deceased;
- ☐ g) adult sibling of deceased;
- ☐ h) adult nephew or niece of deceased;
- ☐ i) adult next of kin of deceased, determined under sections 89 and 90 of the Estate Administration Act;
- ☐ j) minister under the Employment and Assistance Act or the official administrator under the Estate Administration Act;
- ☐ k) an adult person having a personal or kinship relationship with the deceased, other than those referred to in paragraphs (b) to (d) and (f) to (i).

Print

Return to Page 1

IF YOU WANT TO DIE NATURALLY AT HOME, CONSIDER THESE STEPS

INDIVIDUAL / FAMILY What to Do **Ahead of Time**

➢ Discuss the option of an in-home death with your physician/nurse practitioner and community nurse.

➢ Make a written plan with your physician/nurse practitioner and community nurse so you are clear about what will happen and so family, friends and others may support your decisions and respect your wishes and know what to do at the time of death. You need to write in your plan:

1. Who will pronounce death, IF pronouncement is planned. Pronouncement is NOT necessary if a "Notification of Expected Death At Home" form has been completed earlier by you and your doctor or nurse practitioner. The form can be found at www.gov.bc.ca/expectedhomedeath.
2. How your physician/nurse practitioner can be reached
3. What alternate arrangements have been made should your physician/nurse practitioner be unavailable or cannot be reached
4. Which funeral home will be called to transport the deceased

➢ Make prearrangements with a funeral home. Such arrangements will normally involve selecting the funeral home and making plans with the funeral director for transportation of the deceased after death and the method of final disposition. For information on funeral homes in your area, you could contact the B.C. Funeral Association at 1-800-665-3899.

➢ **Ensure that a copy of the NO CPR form is easily available in your home.** If you are away from your home for any reason, take the form with you so it's available should it be necessary.

If the NO CPR form and The Expected Death At Home Form are both completed and the death occurs in the middle of the night you do not have to call the Nurse Practitioner or Physician until early the next day if you are comfortable to wait and do not feel like you need to immediately notify anyone.

FAMILY / FRIENDS What to Do **at the Time of Death**

➢ DO NOT CALL 911, the ambulance, coroner, police, or fire department. Review your written plan for who to contact at the time of death.

➢ CALL family, friends, and the spiritual advisor, if any, you would like to have present.

➢ CALL your Physician or Nurse Practitioner or community health nurse to pronounce death IF a "Notification of Expected Death at Home" form has NOT been completed, AND/OR pronouncement has been pre-planned.

➢ your Physician or Nurse Practitioner or community health nurse cannot be reached, CALL the backup physician/nurse practitioner or community nurse if prearranged.

➢ IF a "Notification of Expected Death At Home" form has been completed AND is in your home, call the funeral home after one hour or more has passed since your loved one's breathing has stopped.

➢ You do NOT need to call a physician or nurse practitioner about completing a Medical Certificate of Death form. The funeral home can contact the physician or nurse practitioner to obtain a signed certificate within 48 hours, because the body cannot be released for burial or cremation without it.

People to Call	**Name**	**Telephone Number**
Physician/Nurse Practitioner		
Alternate Practitioner		
Community Nurse		
Funeral Home		
Spiritual Advisor		
Home Support Agency		
Hospice Program		
Family and Friends		

Powell River Division of Family Practice A GPSC initiative
Vancouver Coastal Health Promoting wellness. Ensuring care
SharedCare Partners for Patients
British Columbia Ministry of Health

Return to Page 1

CAREGIVER INFORMATION SHEET

WHAT TO CONSIDER WHEN CARING FOR SOMEONE WHO IS DYING AT HOME

This is written for families and caregivers of the person who has made the choice to die at home.

Changes that occur as a person dies will vary from one person to the next. Some changes may be unsettling and are usually more difficult for you to watch than for the person to experience. The more families and friends understand what is happening during the dying process, the better you will be able to handle the situation and manage caring for your loved one at home. An important goal when death is near is to do what the person with an advanced terminal illness would choose. Ideally, he or she knows what is happening and has participated in making decisions about how to live and prepare for death. Discussing these wishes with you, your family, and your physician is important. If this has not happened, you should aim to do what this person would want. Following the wishes of the person who is dying may mean making decisions that are different from what you would choose for yourself.

WHAT YOU CAN DO TO HELP

Help with comfort and rest

Continue giving medicine for pain on a regular basis as ordered by the physician. If a person cannot tell you about pain, watch for tense body posture, clenched fists, frowns, restlessness, moaning, or attempts to turn over. Soft music can be very soothing, even when a person is not conscious. Turn the patient every few hours and rearrange his or her position with pillows (ask the physician or nurse to show you how if you are unsure or worried about how to do this). Give back rubs and maintain skin moisture with lotion. Try to avoid using bright lights. Moisten the patient's eyes, using a warm damp cloth and their lips with lip balm to prevent dryness. Talking and touching are comforting to both you and the patient, although s/he may often not respond.

Prepare for physical and emotional changes

As people die, they become extremely tired and weak. Swallowing fluids and taking medication gets harder. Breathing changes and becomes noisy and irregular, the person may even periodically stop breathing at times and sound as though they are gasping , which can often be frightening. The person will gradually respond less and less to you but continue to keep talking and holding hands for comfort. Discuss any symptoms that you are concerned about—such as pain, difficulty swallowing, noisy breathing or general anxiety and discomfort, with the physician or nurse. Medications can be ordered to help keep your loved one comfortable and are often available in a variety of different routes for administering. Prescriptions will need to be filled through your local pharmacy.

Avoid calling 911 or an emergency team

When you or someone else calls 911 or the emergency number in your area, you need to remember that the paramedics will arrive expecting to save a life or give "aggressive" treatment in an attempt to restore life—they may even move the person from the home to the hospital. Have an emergency plan in place and a network of people to call, such as phoning a family physician or palliative care specialist first. Keep phone numbers of physicians, home care nurses, palliative care team staff and other people you may need to contact readily available. Know who to call when worried or concerned.

Prepare a list of people to call near the time of death

Decide who you and your loved one would want to visit the home near the time of death—to say a final goodbye. Also make a list of people who want to be notified when the person dies. Decide who would be most helpful to you at this difficult time and have them come over to help with phoning and anything else that you may need. Ask certain adults to be “on-call” to help with any younger children if this is needed. Decide if clergy or a bereavement counselor should be called before or at the time of death.

Prepare for the funeral home ahead of time

Select a funeral home and inform them that you expect a natural death at home in the near future. The funeral home staff can tell you and your loved one about the costs and different kinds of services available so that you can both be thinking about what you would like and afford. Some families prefer to make these arrangements early so that the person with an advanced illness can help in the planning. Others make these arrangements just before death occurs. The doctor or nurse who confirms that death has occurred will usually call the funeral home for you. This does not need to be done immediately.

WHAT TO ANTICIPATE AND RECOGNIZE WHEN THE END OF LIFE IS NEAR

No matter how much you prepare for this moment, death arrives in its own time and in its own way. The experience of dying is different for every person and for every family. What is important is to do whatever is felt to be of help and comfort during this time. The moments around the time of death are often full of emotion for many reasons, and you may need help from a home care nurse or other health care professionals at this point—in order to keep your loved one comfortable.

Next -->

Return to Page 1

At the end of dying is death itself. You will know this has happened because the chest will not rise and you will feel no breath from the person's nose. The eyes may be glassy (if they are open). You will not feel any pulse in the places where you felt it before. When your realize someone has just died, it is a very "still" and quiet moment. After your loved one has passed on, take as much time as you need to say your goodbyes. The attending physician or nurse will need to see your loved one and sign a death certificate, of which you will later need to obtain a copy from the funeral director. Medications will also need to be discarded appropriately; ask your physician or nurse what to do with these. Either the physician or the nurse will call the funeral home for you and arrange to have them respond when you are ready to have them come to your home.

WHAT IF CARING FOR YOUR LOVED ONE AT HOME DOES NOT WORK?

Helping someone to die at home is hard work, and you may need to take the person you are caring for somewhere else to live out the final days of his or her life. Periodically ask yourself if the person you are caring for is comfortable and if his or her wishes are being followed. Also ask yourself if you have the physical and emotional strength to give the care that is needed. If not, it is important that you speak with the doctor or nurse. You can still help to give care for your loved one in the hospital, palliative care unit, nursing home, or hospice—having a sense that the person is comfortable and that you are meeting their needs in this way is important for you and your family to know.

HELP for YOU and YOUR FAMILY

Remember that your are not alone, there are many people ready to help when a family is preparing for an expected death-at-home. Consider discussing the following with your physician or home care nurse, in order to connect you with some helpful resources in your community—so that you can reach them when you are ready and need to.

RESOURCES to consider contacting in your community:

Spiritual Support Services -

Grief Counseling and Bereavement Services for Family and Caregivers -

Website Resources:

The Canadian Cancer Society http://www.cancer.ca/english/index.asp
The Canadian Hospice Palliative Care Association http://www.cpca.net
Alberta Palliative.net – A Caregivers Guide http://www.albertapalliative.net/APN/CGG/CGGIdx.html/
American College of Physicians Home Care Guide for Advanced Cancer
http://www.acponline.org/public/h_care
Caring for Your Loved One at Home: P.E.I. Guidelines for Managing the Expected Home Death
http://www.gov.pe.ca/photos/original/hss_homedeath.pdf
Preparing for An Expected Death at Home. Nova Scotia Department of Health Publication.
http://www.gov.ns.ca/health/downloads/preparing_at_home.pdf

IMPORTANT PHONE NUMBERS:

FAMILY PHYSICIAN:

PHARMACY:

HOME CARE NURSE:

CLERGY/SPIRITUAL SUPPORT:

PALLIATIVE CARE TEAM:

FUNERAL HOME/DIRECTOR:

RESPITE SERVICES:

LAWYER:

OTHER CONTACT NUMBERS (friends, family, community services):

Adapted by The Foundation for Medical Practice Education with permission from:
1. The American College of Physicians Home Care Guide for Advanced Cancer. The American College of Physicians is not responsible for this adaptation. To view the complete original document visit: http://www.acponline.org/public/h_care/index.html
2. Preparing for An Expected Death at Home, Home Care Nova Scotia, 2000 http://www.gov.ns.ca/health/

Return to Page 1

Clinical Practice Guidelines for Conducting Family Meetings in Palliative Care

1. Preparing for a family meeting

a) On admission to the palliative care unit the relevant health professional should introduce the purpose of a family meeting and offer a family meeting to all lucid patients. This discussion should incorporate the role that palliative care has in supporting families as well as the patient.

b) Ask the patient to confirm one or two key family carers and/or friends who they approve to be involved in medical and care planning discussions. Note this in the medical record.

c) Conduct a family genogram to determine key relationships within the patient's family. It could be introduced thus: "Can I spend a few minutes just working out who is in your family?"

d) Seek the patient's permission to arrange a family meeting and ask if they have any particular issues/concerns or questions they would like discussed at the meeting. If the patient does not want to attend, seek their permission to conduct a meeting with key family and/or friends (as above). If the patient is unable to make an informed decision, offer the meeting to the next of kin or key family/friends who have been identified to receive information and care planning decisions related to the patient. Note: Where a patient has no family or appropriate proxy a legal guardian may need to be appointed.

e) Identify the most appropriately skilled person from the multidisciplinary team to convene the family meeting. This person will take responsibility for scheduling, invitations and coordination. Ideally this person should also act as the primary contact point for the key family carer(s).

f) Contact the primary family carer(s): provide an overview of purpose of the family meeting; offer to convene a meeting at a mutually acceptable time. Advise the carer that the meeting time will be confirmed in due course (i.e., once other attendees are arranged). Where pertinent, and if resources allow offer to conduct the meeting via teleconference. Establish the main questions and issues that the family carer would like discussed (refer Table 3). If the patient is participating in the meeting ask him/her to identify their key concerns.
Note: If significant family conflict (or other major issue) is identified consider referral to a practitioner who is trained to work with complex issues within families (e.g. family therapist or health psychologist).

g) Determine which health care professionals should attend the family meeting. Invite key health care professionals based on the identified needs of the patient and family carer. The number of staff should be restricted, inviting only the relevant health professionals, so that the patient and family/friends do not feel overwhelmed. Note: Include a professional interpreter if required.

h) Confirm the family meeting time and location. Inform attendees of the scheduled start and finish time for the meeting. A comfortable room free of interruptions (including pagers and phones), tissues made available and conducive seating arrangements is recommended.

2. Conducting a family meeting

a) Introduction

Chairperson to:

i) Thank everyone for attending and introduce him/herself and invite others to introduce themselves and state their role.

ii) Establish ground rules in a non patronsing way e.g. *"We would like to hear from all of you, however if possible could one person please speak at a time, each person will have a chance to ask questions and express views."* Request no interruptions such as phones etc.

iii) Indicate the duration of meeting (recommended maximum time of 60 minutes).

b) Determine the understanding of the purpose of the family meeting.

Next -->

Return to Page 1

Chairperson to:

i) Briefly **outline** the broad purpose of the family meeting (based on previous steps), and then confirm with the family and patient that their interpretation of the purpose of the meeting concurs.

For example:

"*We arranged this meeting to consider discharge planning options. Is this your understanding of the purpose of the meeting?" (If not reframe the meeting's purpose)*

or

"From the things you mentioned on the questionnaire what is the most important thing you would like to discuss?"

or

"How could we be most helpful to you today?"

ii) Ask the patient/family if there are any additional key concerns, and if pertinent, prioritise these and confirm which ones will be attempted to be dealt with at this meeting (others can be discussed at a future meeting or can perhaps dealt with on a one on one basis).

iii) Clarify if specific decisions need to be made (e.g. if the patient is to go home or not).

c) Determine what the patient and family already know. Possible questions may include,

"*What have you been told about palliative care*" as a way of clarifying, confirming etc.

"*Tell me your understanding of the current medical condition or current situation*?"

If pertinent provide information (in accordance with desire) on the patient's current status, prognosis and treatment options.

Ask each family member in turn if they have any questions about current status, plan and prognosis. Helpful questions may include, "*Do you have questions or concerns about the treatment or care plan?"*

<u>For family discussion with non-competent patient (i.e. cognitively impaired or imminently dying).</u>

Ask each family member in turn:

"*What do you believe your relative/friend would choose if they could speak for himself/herself?"*

"In the light of that knowledge, what do you think should be done?"

d) Address specific objectives of the meeting (as previously determined).

e) 'Check in' periodically throughout with the patient and family carer to see if the discussion seems to be valuable and is in keeping with their needs e.g. *"Are we on track?"; "Is this what you wanted from today's meeting?"; "What haven't we touched on that's important to you?"*

Also consider taking a short break during the meeting (to give participants time to digest information) and then allow some time to refocus.

f) Offer relevant written or audiovisual resources. Examples include guidebooks, brochures, enduring power of attorney documents, advance care directive information and so forth.

g) Identify other resources, including possible referral to other members of the multidisciplinary team. Suggest scheduling a follow-up meeting if pertinent.

Next -->

Return to Page 1

h) Concluding the discussion.

Summarize any areas of consensus, disagreements, decisions and the ongoing plan (i.e. clarify next steps) and seek endorsement from attendees (e.g. *"Are we all clear on the next steps?")*

Emphasize positive outcomes arising from the meeting.

Offer final opportunity for questions, concerns, or comments. E.g. *"What hasn't been covered today that you would have like to discuss?"* or *"Are there any questions you had that haven't been answered yet?"*

Remind patient and family carers to review the recommended written resources.

Identify one family spokesperson for ongoing communication.

Thank everyone for attending.

3. Documentation and follow-up

a) Document who was present, what decisions were made, what the follow-up plan is and share this with the care team (see Table 4).

b) Offer the patient/family a copy of the main content of the meeting and file a copy of this document in the patient's medical record.

c) Liaise with the primary family carer within a few days after the meeting to determine if the meeting was helpful (see Table 5)

d) Maintain contact with the key family spokesperson, including attending scheduled follow-up meetings or telephone calls as needed.

Hudson *et al. BMC Palliative Care* 2008 **7**:12 doi:10.1186/1472-684X-7-12

Pre-Family Meeting Primary Family Carer Questionnaire

Nb Conducted by phone [] or face to face [] by Family meeting convenor ..... [insert name]

Now that I have explained about the family meeting and you have agreed to attend it would be useful for us if we had some more information in order to prepare for the family meeting.

What are the main issues for you at the moment?

(a) Greatest concern:

.....

(b) Second greatest concern:

.....

How upset/worried are you about these concerns? *(Place a cross on the line)*

---

(1) Not at all *As worried as I could possibly be (10)*

How often do these concerns arise? *(Place a cross on the line)*

---

(1) Not at all *All the time (10)*

Are there other difficulties you are coping with now? Please outline below:

.....

.....

How much is the problem (or problems) interfering in your life? *(Place a cross on the line)*

---

(1) Not at all *Dominating my life completely (10)*

How confident do you feel in dealing with the problem(s)? *(Place a cross on the line)*

---

(1) Not at all *Extremely (10)*

What questions would you like to ask at the family meeting?

.....

If you think of other questions between now and the family meeting, please write them down and bring them with you to the meeting.

Adapted with permission from Single Session Therapy Resource Guide (The Bouverie Centre 2006)

Hudson *et al. BMC Palliative Care* 2008 **7**:12 doi:10.1186/1472-684X-7-1

Outcome of the Family Meeting

Below are key points to be recorded at the completion of the family meeting by the Family Meeting's Facilitator.

A copy should be provided to the patient and family carer and one copy kept in the medical record.

Date of meeting: _____

Name of family meeting facilitator: _____

Proposed purpose of the meeting: _____

FAMILY MEMBERS PRESENT

Name: Relationship:

Name: Relationship:

Name: Relationship:

STAFF MEMBERS PRESENT

Name: Role/Discipline:

Name: Role/Discipline:

Name: Role/Discipline:

KEY ISSUES RAISED AT THE MEETING

_____

_____

KEY ACTIONS FROM THE MEETING

Current Situation	Goal	Action	Key Person to follow up	Review Date

Adapted (with permission) from Single Session Therapy Resource Guide (The Bouverie Centre 2006)

Post-Family Meeting Primary Family Carer Questionnaire

Nb Conducted by phone [] or face to face []. Completed by ..... [insert name]

As a follow up to the recent family meeting we are interested in finding out how things are for you at the moment. Before the family meeting

You nominated:

.....

as the main problem to be discussed at the family meeting, and

.....

as your second greatest problem.

How upset/worried are you about this problem (or these problems) at the present time? *(Place a cross on the line)*

---

(1) Not at all *As worried as I could possibly be (10)*

How often do these problems happen? *(Place a cross on the line)*

---

(1) Not at all *All the time (10)*

How much is the problem (or problems) interfering in your life? *(Place a cross on the line)*

---

(1) Not at all *Dominating my life completely (10)*

In what ways?.....

How confident do you feel in dealing with the problem(s)? *(Place a cross on the line)*

---

(1) Not at all *Extremely (10)*

You nominated the following questions as those you would like addressed in the family meeting:

.....

To what extent do you feel these questions were addressed?

.....

Office use only:

	Pre-session	Post-session	Difference
How upset/worried:	.....	.....	.....
Problem frequency:	.....	.....	.....
Life interference:	.....	.....	.....
Confidence:	.....	.....	.....

Hudson *et al. BMC Palliative Care* 2008 **7**:12 doi:10.1186/1472-684X-7-12Table 5

Online Resource Guide for Caregivers

American Academy of Hospice and Palliative Medicine
The American Academy of Hospice and Palliative Medicine website is home to many resources including single page peer-reviewed summaries on a wide variety of palliative topics called "Fast Facts."
Website: www.aahpm.org/

BC Bereavement Helpline

BC Bereavement Helpline (BCBH) is a non-profit, free, and confidential service that connects the public to grief support services within the province of BC. The BCBH assists the bereaved and their caregivers in coping and managing grief.

Phone: 1-877-779-2223
Website: www.bcbereavementhelpline.com/

BC Hospice Palliative Care Association (BCHPCA)

The BC Hospice Palliative Care Association is an umbrella organization whose mission is to provide a leadership role for its member organizations and individuals to ensure quality of care for British Columbians faced with a life-threatening illness, death and bereavement.

Website: www.hospicebc.org

Canadian Hospice Palliative Care Association (CHPCA)

The Canadian Hospice Palliative Care Association is the national voice for hospice palliative care in Canada. It is a national charitable non-profit association whose mission is to provide leadership in hospice palliative care in Canada.
Website: www.chpca.net

BC Ministry of Health Services - Palliative care benefits program

The BC Palliative Care Benefits program supports individuals of any age who have reached the end stage of a life-threatening disease or illness and who wish to receive palliative care at home.
Website: www.health.gov.bc.ca/pharmacare/outgoing/palliative-patientinfo.pdf

Canadian Virtual Hospice
Canadian Virtual Hospice was created in recognition that Canadians dealing with life-threatening illness and loss need more information and support than they may be able to find in their home communities. The Virtual hospice is an interactive network for people (including health professionals) dealing with life-threatening illness and loss.
Website: www.virtualhospice.ca/

A Caregiver's Guide, A Handbook about End-of-life Care

A Caregiver's Guide, A Handbook about End-of-life Care, assists family caregivers by complementing the guidance and information they receive from palliative care and homecare professionals

Website:
www.stlazarus.ca/english/projects_pages/palliativecare_pages/caregiversguide.html

Family Caregiver Network Society (Victoria)

Offer a variety of support to family caregivers.
Tel. 250-384-0408
Website: http://www.fcns-caregiving.org/contact-us/

Palliative Drugs

Palliative Drugs was founded to promote and disseminate information about the use of drugs in palliative care.
Website: www.palliativedrugs.com/

Health Canada Compassionate Care Benefits

The Compassionate Care Benefits program provides Employment Insurance (EI) benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months).

Website: www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Home and Community Care services

The Home and Community Care services of the BC Government website provides information on palliative care co-ordination and consultation, professional nursing services, community rehabilitation services, home support and respite for the caregiver.

Website: www.health.gov.bc.ca/hcc/index.html

My Voice© A workbook for Advance Care Planning – Feb 2012

My Voice is a workbook for Advance Care Planning

Website:

http://www.health.gov.bc.ca/library/publications/year/2012/MyVoice-AdvanceCarePlanningGuide.pdf

Here are some more websites that might be of interest and/or assistance:

ALS Society

ALS: Primary Care guide available which includes a section on palliative care
Website: www.als.ca/

BC Cancer Agency (BCCA)
The BC Cancer Agency, an agency of the Provincial Health Services Authority, provides a province-wide, population-based cancer control program for the residents of British Columbia. The BC Cancer Agency's mandate covers the spectrum of cancer care from prevention and screening, to diagnosis, treatment, and through to rehabilitation.
Website: www.bccancer.bc.ca

BC Housing
Is a provincial crown agency that provides affordable housing options for British Columbians in greatest need.
Website: www.bchousing.org

Burnaby Seniors Outreach Services Society Caregiver Support Program
Promotes seniors' independence, self esteem and the achievement of individual goals.
Phone: 604-291-2258
Website: http://www.bsoss.org/

Citizenship and Immigration Canada
Administers the Immigration and Citizenship Act and all related regulations.
Website: www.cic.gc.ca

Law Students Legal Advice Program (Lslap)
A non-profit society run by UBC law students to provide free legal advice at clinics located in the Greater Vancouver Region.
Website: www.lslap.bc.ca

Leukemia and Lymphoma Society of Canada
The Leukemia & Lymphoma Society is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. The Society's mission: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.
Website: www.LLS.org/canada

MS Society of BC
The MS Society of BC has an excellent Resource Disability Benefits Manual on their website, which includes many useful community resources.
Website: www.mssociety.ca/bc

National Cancer Institute
This is an American website that provides information on cancer topics, clinical trials, statistics and research.
Website: www.cancer.gov

HealthLinkBC
This website provides non-emergency health information to the residents of BC through combined telephone, internet, and print resources.

Website: www.healthlinkbc.ca/, including: Should I receive CPR and life support?
www.healthlinkbc.ca/kb/content/decisionpoint/tu2951.html

North Shore Community Resources Caregiver Support Program
Offers events and network groups for caregivers to find out how to take care of yourself and ensure you get the support you need.
Tel. 604-985-7138
http://www.nscr.bc.ca/information/caregiver.html

People's Law School
This is a website by a registered non-profit society whose goal is to help you learn about your rights and responsibilities under the law.
Website: www.publiclegaled.bc.ca

Provincial Taxation
This website provides information on the fuel tax refund programme for persons with disabilities.
Website: www.rev.gov.bc.ca

Public Guardian and Trustee of BC
This website includes information on wills and estate planning, healthcare decision-making, and guardian issues.
Website: www.trustee.bc.ca

Representation Agreement Resource Centre
This website had resource information on legal healthcare and financial decision-making.
Website: www.rarc.ca

Seniors Housing Information Programme (SHIP)
Is a non profit society whose mandate is to gather and provide information on housing and related services for seniors living in or wishing to live in the Lower Mainland, which will assist in their general well being.
Website: www.seniorshousing.bc.ca

UBC Dental School
Has a dental clinic.
Website: www.dentistry.ubc.ca/dental_clinic/how_to_become.asp

UK NHS Resource Kit for Symptom Management in Heart Failure
Website: www.heart.nhs.uk/endoflifecare/resource_kit.htm

Volunteer Richmond (Richmond Caregiver Program)
Offers the Caregivers Education and Support Program which is for unpaid caregivers who provide care and support for older adults (55 plus), at home, in the community or in a care facility in Richmond. This free 5-week education series will provide caregivers with the tools to support their loved one and, more importantly, the skills to remain healthy and well themselves.
Phone: 604-279-7020
Website:
http://www.volunteerrichmond.ca/Programs/SeniorsPrograms/CaregiversEducationAndSupport.aspxasp

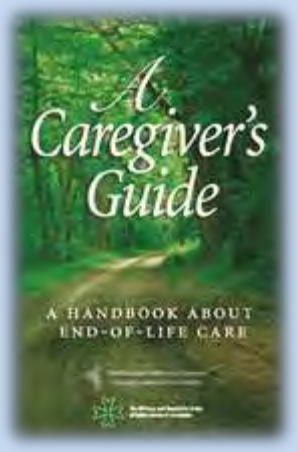
VCH Caregiver Support Program
Offers programs and free services to support family and friend caregivers
Tel. 604-877-4699
Website: http://caregivers.vch.ca/

Based on material created by Dr. Tim Sakaluk for the 2008 GP Palliative Care Education Sessions

Return to Page 1

When Someone Dies Handout

Preparing for the Death of a Loved One
English
Cantonese
Punjabi



A Caregiver's Guide

CANADIAN Virtual Hospice
Information and support on palliative and end-of-life care, loss and grief.

Canadian Virtual Hospice

Vancouver CoastalHealth
Promoting wellness. Ensuring care.

Return to Page 1

Print

When Someone Dies...

Providence HEALTH CARE
How you want to be treated.

North Shore, Sea to Sky,
Sunshine Coast, Powell River,
Richmond and Vancouver

Return to Page 1

Information for Family and Friends of a person who has died within hospital, home or a care facility.

We know this is a difficult time for you. All the people who helped care for your relative or friend wish to offer their sympathy.

If you find you have questions in the days ahead, please call:

_____

at _____

The Hospital Unit/Facility/Health Unit which cared for your relative or friend is:

_____

These are the names of the health care members who spoke with you:

Nurse: _____

Doctor: _____

Chaplain: _____

Social Worker: _____

Other: _____

Primary contact: _____

Phone number: _____

The death of a relative or friend is one of the most stressful things that happens in life. If death was sudden or unexpected, your feeling of shock can be overwhelming. Even when the person was ill and death was expected, it is still hard to be prepared.

As you try to deal with your grief, it can be difficult to remember what the nurse, doctor or social worker said to you. It can be even more difficult to think of what you need to do next.

We hope this booklet will answer some of your questions, and help you as you make the necessary arrangements. It is important at this time to remember to look after yourself. This booklet explains about some of the feelings you may have and suggests ways of caring for yourself. There are many people and organizations that can help you; we've included a list of some of these in this booklet.

Return to Page 1

Table of Contents

Questions you may have **6**

What happens immediately after the death?
What about organ donation?
What is a Coroner's Case?
What is an autopsy?
What is a death certificate?
Who makes the funeral arrangements?
What happens to clothing and valuables?
Making the decisions that have to be made next

What do you do now? **9**

What to do first
Who to notify
Planning the funeral
Special situations
Survivor benefits

Caring for yourself **22**

Grief
Children
Your own well-being

Resources **26**

Recommended readings

Return to Page 1

Questions you may have

What happens immediately after the death?

A doctor or nurse pronounces that death has occurred.* In hospital, whenever possible, the body is left for a short time on the nursing unit so that if you wish, you can spend some time there. Then the body is taken to the hospital morgue until arrangements are made for release to a funeral home. If your religious or cultural traditions or the family's personal wishes require direct transfer to the funeral home, this can usually be arranged (unless the death is a "coroner's case"). In these situations, it is possible to have the funeral home come directly to the unit and pick up your relative or friend. Please advise the unit in advance if this is your wish. Delays may occur in coroner's cases.

In facilities or at home, the body is picked up by the funeral home and taken directly to the funeral home.

What about organ donation?

There are provincial laws about organ donation. The hospital is expected to ensure that the wishes of people who have died are respected in regard to donating their organs. The hospital is responsible to approach families of potential donors to seek confirmation of what the patient may have documented or discuss what he or she would have wanted. Organ donation may not be possible, depending on the person's age, type of illness and where the person has died, if outside the hospital. Eyes are the most common organ donated. Please let nurses or doctors know if the person wished to be a donor or if you want more information about organ donation. You can also visit the BC Transplant website, www.transplant.bc.ca.

**Expected/planned deaths in the home may not require pronouncement if appropriate prior arrangements have been made with the family physician and funeral home. For more information refer to the Joint Protocol for Expected/Planned Home Deaths at* www.healthservices.gov.bc.ca/hcc/endoflife.

What is a Coroner's Case?

Sometimes the law requires that death must be reported to the coroner. This happens when a sudden or unexpected death occurs, and in other cases specified by law or by facility/hospital policy. The coroner discusses what has happened with the family doctor and any specialists who were involved. The coroner then decides whether or not an autopsy is needed. If an autopsy is needed, this may mean that the body cannot be released immediately. If so, the coroner will notify the next-of-kin. The coroner's office will try to accommodate your religious and cultural traditions concerning death.

What is an autopsy?

An autopsy is surgery that is done after a person dies to find out what caused the death. Only a few people will need an autopsy. Sometimes the doctor may ask the next-of-kin to sign a consent form giving permission for an autopsy. The autopsy findings are sent to the deceased's family doctor. The family can learn of the results through the family physician.

What is a death certificate?

At the time of death, the doctor completes the Medical Certification of Death. This form is needed by the Department of Vital Statistics to issue the Death Certificate (which is not the Medical Certification of Death).

A death certificate is a legal document that is needed to settle the deceased's affairs. You can get the certificate from the Department of Vital Statistics or the funeral home. **You may need several copies of this certificate.**

Return to Page 1

Who makes the funeral arrangements?

It is up to you to choose a funeral home or memorial society. Your religious advisor can help. Social Workers can also assist. When you have made your choice, the funeral director will ask you to sign a release form so they can bring the body to the funeral home. (More about planning the funeral on page 14.)

What happens to personal belongings?

In hospital, if you did not take your relative's or friend's valuables with you when you left the hospital, call the hospital cashier's office to make arrangements to get them. It is important to phone before coming. Either the Executor of the estate named in the will, or the next-of-kin on the hospital registration can pick up belongings.

VGH: 604-875-4068
Monday to Friday
8:00 a.m. - 5:00 p.m.

LGH: 604-984-5862
Monday to Friday
8:00 a.m. - 4:30 p.m.

UBCH: 604-822-7555
Monday to Friday
8:30 a.m. - 4:30 p.m.

Richmond: 604-278-9711
Check with Switchboard

St. Paul's Hospital: 604-682-2344

Clothing is usually kept on the nursing unit for 48 hours. Please call the unit before coming to get it.

In care facilities, personal belongings, furniture, and equipment are removed from the resident's room and stored if the family is unable to take them away at the time of death. These items are usually picked up within a few days of the death.

If the person died at home, families often wonder about disposal of medications which are left over. Although these medications cannot be re-used, families can return these medications to the Pharmacy.

Making the decisions that have to be made next...

When you get home, there will be many things that need to be done. Remember that whether the death was sudden or expected, it is always a very stressful time.

Try not to make decisions too quickly. Try to take care of your own physical and emotional needs. Let others help you.

What do you do now?

What to do first ...

When someone dies, there are many personal and legal things that need to be done. It can be confusing and worrisome to try to remember all the details. You might use the blank pages of this book to make lists and keep notes. Friends and family usually want to help. You might let them deal with the daily household activities or phone calls while you make the funeral arrangements.

Here are some things you will need to do:

- Make a list of relatives and friends who need to be notified. Find out if people who live out- of-town want to come to the funeral or memorial service. This may make a difference as to when you decide to hold the service.

- Contact the funeral home or memorial society and arrange a meeting to discuss the funeral arrangements. Further on in this booklet you will find some information about planning the funeral. Your health care worker will be able to provide some information pamphlets as well.

Return to Page 1

- Locate the will, if there is one. If it is necessary, banks are able to open a safety deposit box to search for a will. The deceased's lawyer may have a copy. Some people register the location of their will at BC Vital Statistics. Call 1-250-952-2681 or visit one of the Vital Statistics offices (in Vancouver, the office is at 605 Robson Street, Room 250). BC Vital Statistics has a website: www.vs.gov.bc.ca which has information in Punjabi, Chinese and Vietnamese as well as English.

- If there is a will, there will be an executor. This person is responsible for carrying out the instructions in the will.

- Gather together the important papers of the deceased:
  - Birth, marriage and divorce certificates, if available
  - Citizenship or Immigration papers
  - Social Insurance Number
  - War Veterans Regimental Number
  - Pension papers and numbers
  - Indian Status Card

- You will need this information to get the Death Certificate and for settling other legal matters.

Notes

Return to Page 1

Who to notify ...

The following should be notified of the death:

- The deceased's employer.
- Life insurance companies. Survivor benefits should be applied for as soon as possible. Remember that the deceased may have had a life insurance policy with the employer as well as with private companies.
- Health care insurance plans covering the deceased.
- Automobile insurance company, and the nearest motor vehicle office.
- Banks where the deceased had accounts.
- Credit card companies and other creditors. (Some debts may be covered by insurance clauses that cancel all debt.)
- Pension authorities: Old Age Security (OAS), Canada Pension Plan (CPP), company pension, and any others. The phone number for OAS/CPP is **1-800-277-9914** or Vancouver office at **604-681-8253**.
- Union, Legion and any clubs or organizations of which the deceased was a member.
- Remember to notify the deceased's landlord, cancel utilities, newspaper and magazine subscriptions. If the deceased lived alone, notify the post office and tell them where to send any mail.
- If the deceased is a Status Indian, contact Indian and Northern Affairs, 1-888-917-9977 or consult the website www.ainc-inac.gc.ca "Wills and Estates"

Notes

Return to Page 1

Planning the funeral ...

(also see Special Situations, page 17)

Whether you have experienced the death of someone close to you before, or this is the first time you have had to make funeral arrangements, the shock and grief you are feeling can leave you confused about what to do.

We hope the following will be helpful as you make your plans. Above all, take time to consider your decisions. Don't be rushed. For expected/planned deaths, some of the arrangements can be made in advance of the death.

- Whatever you decide - whether it is a religious or secular service (or celebration of life), private or public, elaborate or simple, burial or cremation - it can be healing to mark the death of a loved one with a service or ritual that has meaning for the people involved.

- When you are deciding on the date for the service, remember that distant relatives and friends will need time for travel. Remember, too, that if the death is a coroner's case or an autopsy is needed, there may be a delay before the body is released to the funeral home.

- Some airlines offer discounted rates (called compassionate fares) for travel to a funeral. You must ask the airline when making travel arrangements.

- The deceased may have left written instructions about the funeral in or along with a will. Check with the deceased's lawyer or executor before making funeral plans.

- If you have a religious/spiritual affiliation, call the leader of your religious/spiritual community who will meet with you and your family to discuss what kind of funeral or memorial service will be appropriate. Keep in mind any wishes that the deceased may have expressed.

- If you have no religious affiliation, a discussion with family or friends can help you decide what kind of funeral or memorial service to have. Tell the funeral home your wishes - they will help you find the appropriate person to conduct the service. Funeral celebrants are available to officiate services. Again, keep in mind the wishes of the deceased.

- You may already know which funeral home or memorial society you wish to use. If not, ask friends, your religious advisor, cultural or ethnic leaders. Some funeral homes specialize in providing services for particular religious or ethnic groups. Funeral homes all have 24-hour phone service.

- The cost of funeral services vary greatly so compare costs. There are a variety of packages; some can be more elaborate and more expensive than you may be able to afford.

- When you go to the funeral home to arrange the funeral, it always helps to take a trusted friend or relative with you to help with the decisions.

- Be sure to consider what can be reasonably afforded and discuss this openly with the funeral director. Before you sign the contract for the funeral, be sure that the total cost of the services is clear to you, and that you agree with it.

- If not already done, the funeral home or memorial society will make arrangements to move the deceased's body from the hospital.
  Funeral homes can also assist with arrangements to transport the body home if the person died away from home.

- The website www.bcfunerals.com has helpful information including a listing of funeral homes in BC.

Return to Page 1

- The funeral home will help you write an obituary notice and place it in the newspaper, and will help you get the death certificate. Ask for several copies of the Death Certificate as you may need them to settle the deceased's affairs. The funeral director will need detailed information on the deceased's date and place of birth, parents, marriages, divorces, surviving family and other such information.

- The funeral director will need to know the names of pallbearers if you plan to have them. Be sure to check with the relatives or friends you have chosen to be sure they will be able to perform this service.

- Decide about flowers. Some people prefer to suggest donations to a charitable organization. This should be mentioned in the obituary notice.

Special Situations ...

- You may wish to have your relative or friend buried or cremated in another city. If the funeral will be in another province or country, you will need to make arrangements with a funeral home in that province or country. They will contact the people in Vancouver to transfer the deceased's body. The funeral director will then make the arrangements you want. Be sure to confirm the costs of a transfer.

- **If money is a problem:**
  - You might be eligible for help from a union, society, lodge or other association to which the deceased belonged. Contact the appropriate organization before you make any arrangements.

  - Veterans with limited financial means may qualify for a burial provided by the Last Post Fund. Contact the local Legion office.

  - The Ministry of Human Resources provides funeral arrangements for those who are on social assistance or who have no ability to pay.
    Next-of-kin must contact the Ministry before making any arrangements ***(604-660-3352)****. Funeral home choices may be limited for ministry sponsored arrangements.*

  - If the deceased has no relatives or friends able to provide the funeral, the Office of the Public Trustee will do so **(604-660-0963)** or refer to the website: www.trustee.bc.ca

Return to Page 1

Notes

Survivor Benefits ...

At the time of a death, those left behind may not be thinking of benefits for which they are eligible. You may even feel that this is not the time to be thinking about money. Do not hesitate to apply for any benefits you are entitled to.

If you are eligible for any of the following benefits, you must apply. They will not just come to you automatically. You will need to supply a Death Certificate and some of the other documents you have gathered together.

- **Canada Pension Plan**

  If the deceased has made contributions to the plan, survivors may be entitled to:

  a) a lump sum payment which can contribute towards funeral costs;

  b) pensions for the surviving wife or husband and for children under 18 years of age or children up to the age of 25 who are full-time students.

  To apply, call Health and Welfare Canada, Income Security Programs. It is listed in the Blue Pages of your phone book, Government of Canada section. OAS/CPP phone number is **1-800-277-9914** or check the website: www.canadabenefits.gc.ca. This website provides information on dealing with a death, including survivor pension information and the one-time payment (called the *Death Benefit*).

- **Company or Union plans**

  Check with the union or the employer.

Return to Page 1

- **Workers' Compensation**

  If your relative or friend died of a work-related accident, Workers' Compensation may provide benefits that cover burial costs, the cost of transporting the deceased to the place of burial, and an emergency lump sum payment. Application for these benefits is usually made by the deceased's employer through the Claims Adjudicator, Compensation Services Division, Workers' Compensation Board. It is in the Blue Pages of your phone book, Provincial Government section or refer to the website: www.worksafebc.ca.

- **Motor Vehicle Insurance**

  If the deceased died from injuries caused in a motor vehicle accident, the insurance company may provide a benefit. Contact your nearest Claims Centre. 604-520-8222 (Vancouver)

- **Criminal Injuries Compensation**

  Compensation may be provided for the surviving family of a crime victim. Contact the Victim Services Unit of your local police department or go to Government of BC website at www.gov.bc.ca and search “Crime Victim Assistance Program”.

- **Veterans of limited financial means**

  In some cases, the Last Post Fund will be able to help with funeral expenses and possibly provide a grave marker. Contact the nearest Legion office.

Notes

Return to Page 1

Caring for yourself

Grief

The way we grieve may be shaped by our personality, our culture, our religious or spiritual beliefs, and by the way the person died. Each person feels grief in a very individual way. Some people react with silence, others with an outpouring of feelings.

In your grief, you may feel some or all of the following emotions: fear, anger, anxiety, exhaustion, frustration, loss of control, mistrust, and guilt. Or you may simply feel numb.

These are all normal emotions that can happen when someone has lost a person close to them. They are natural parts of grief.

Your grief process may include the following:

Shock and disbelief

This is usually the first thing people feel at the news of the death of a loved relative or friend. Numbness or denial are responses that protect you when reality is too much to accept.

Anguish and despair

With awareness of the death, a person feels the pain of the loss. The realization often causes extreme anxiety, and feelings of helplessness and hopelessness. The intensity of your feelings can be frightening. It is normal to feel that the pain will never end. You may cry and have sleeping difficulties. Crying is a healthy way of releasing emotion.

You may find yourself painfully searching and pining for the person who has been lost, and preoccupied with thoughts of the dead person. Some people may feel a need to do things which seem strange to others. Some people who have lost their spouse have a need to wear a piece of their spouse's clothing, carry around a personal item that belonged to the deceased person, or have conversations with him or her to "talk things out".

Anger

You may feel irritable and bitter towards friends, family and those you may feel are responsible for the person's death. But what surprises people the most is the anger you may feel towards the person who has died. These feelings of anger are normal. They are not unhealthy unless they are expressed inappropriately, or are harmful to yourself or others.

Guilt

There is a tendency to go over and over the events of the death. Many people blame themselves for things they said or did when the person was alive, and things they didn't say or do. You may find that you are afraid the person who has died will not forgive you, and you feel you will never forgive yourself. Again, those feelings are normal.

Acceptance

The distress caused by a death will change over time. Pangs of grief come from time to time, followed by periods of relative calm. The sense of loss is sometimes revived by an unexpected memory or a significant occasion such as a birthday or anniversary. You will find your own ways to deal with the pain of grief. You may review your loss over and over, saying goodbye each time. Grief is a long and difficult process. No one can say how long it will take, but for most people the first year is the most difficult.

Return to Page 1

Feelings of distress and sadness will become less intense and less frequent over time. It is important to note that grieving is a process of recovery. Like any recovery process, one day you may feel better prepared to get on with your life. The next day the pain of the grief may again feel fresh and you begin to wonder what is wrong with you.

All of these experiences are a normal part of the grief recovery process. If you feel your reactions are harmful to your health or well-being, visit your family doctor or a counsellor.

Children

As difficult as it is for you, the death of a loved one may be even more difficult and frightening for children. Share your feelings of sadness and loss with children in the family. Their questions need to be answered honestly and their fears about the unknown must be addressed. Children grieve according to their development stage, so it will look different from adult grief. More references about children and grief are included at the end of this booklet.

Children need to be reassured that they are not responsible for the death. Encourage children to express their feelings. They should be allowed to participate in any funeral or memorial services and family gatherings.

Your own well-being

During this time, it is important to take care of yourself. Try to get your rest, physical exercise and to eat properly. It can help to treat yourself each week to something special, such as dinner out with a close friend. Remember that your friends, family and spiritual advisor are there to help you. Don't be afraid to ask; friends and family want to help and may not know what you need.

We recommend that during this time you see your doctor for help with your own health and well-being. A list of people and organizations who can help you deal with your grief is included with this booklet.

Your doctor, spiritual advisor, or social worker may know of resources in your community. Please don't hesitate to contact them. They are there to help.

Return to Page 1

Resources

- BC Bereavement Foundation 604-738-9950 www.bcbereavementhelpline.com provides helpful information on how to seek help to assist with grief and has brochures about grief in many languages.

- Griefworks BC exists through a partnership between Children's and Women's Health Centres of B.C. and Canuck Place Children's Hospice. For listings of many bereavement services and resources refer to: www.griefworksbc.com.

- Local churches, family service organizations, hospice groups and health units may offer bereavement counselling or programs

- Living Through Loss Counselling Society of B.C. 604-873-5013 or www.ltlc.bc.ca.

- Victoria Hospice has brochures on their website http://www.victoriahospice.org/cbinfo.html.

- The hospital or care facility may offer resources or have a memorial service to celebrate the lives of individuals who have died in their care.

Recommended readings ...

Suggested books on bereavement for Adults:

- Being a Widow: A Helpful Guide to the Problems of Being a Widow *(VPL)
  Lynn Caine, 1988
  Draws on her own personal experience and the difficult emotions she felt when her husband died. Author does talks and workshops for widows. Valuable self-help book.

- Don't Take my Grief Away: What to Do when You Lose a Loved One.
  Doug Manning, 1984
  The book's basic theme is that it takes time to pass through grief. Practical direct advice.

- Good Grief Rituals: Tools for Healing: A Healing Companion *(VPL)
  Elaine Childs-Gowell, 1992
  A small book, offering activities and ideas for expressing feelings of grief, from letter writing to meditations. Helps with learning how to deal with difficult emotions.

- Grieving: How to go on Living when Someone You Love Dies *(VPL)
  Therese A. Rando, 1988
  Emphasis on differences in personalities and situations of death - includes death of spouse, adult loss of parent, adult loss of sibling.

- Healing Your Grieving Heart - 100 Practical Ideas for Families, Friends and Caregivers
  Alan D. Wolfelt, 2001

*(VPL) available from the Vancouver Public Library

Return to Page 1

- Healing Your Grieving Heart : 100 Practical Ideas *(VPL)
  Alan D. Wolfelt, 1998
  With sensitivity and insight, this book offers 100 practical and down to earth suggestions for healing activities that can help survivors learn to express their grief and mourn naturally.

- Living With Grief: After Sudden Loss Suicide, Homicide, Accident, Heart Attack, Stroke *(VPL)
  Kenneth J. Doka, ed., Hospice Foundation of America, 1996.
  This volume examines the subject of abrupt, unexpected death and its effects and implications for the survivors left behind.

- Tear Soup : A Recipe For Healing After Loss *(VPL)
  Pat Schweibert and Chuck DeKlyen, 1999, 2005
  A beautifully illustrated children's book for adults written about a woman who has suffered a loss and cooks up a special batch of "tear soup".

- The Wilderness of Grief: Finding Your Way
  Alan D. Wolfelt, 2007
  This book takes an inspirational approach by presenting the idea of wilderness as a sustained metaphor for grief.

- Living with Grief: Loss in Later Life
  Kenneth J. Doka, ed., Hospice Foundation of America, 2001.
  This book address the struggles, concerns and issues faced by the bereaved, and those who care for them.

- Living When a Loved One has Died *(VPL)
  Earl A. Grollman, 1995
  A small book of short reflections, dealing with just a little bit of grief at a time. Easily read by someone in the midst of grief, when it is difficult to concentrate.

- Men and Grief: A Guide for Men Surviving the Death of a Loved One *(VPL)
  Carol Staudacher, 1991
  Helpful expert advice for grieving men and professionals in bereavement counselling.

- The Journey through Grief: Reflections on Healing
  Alan D. Wolfelt, 1997
  A small book, easy to read in times of emotional stress. Short reflective notes, step-by-step through the mourning process. Practical at the same time as being spiritual.

- When Bad Things Happen to Good People *(VPL)
  Harold S. Kushner, 1981, 1989
  Inspired by the death of his 14-year-old son, Rabbi Kushner tells how to deal spiritually with an unfair loss or tragedy and writes about the eternal question to God, "Why me?"

*(VPL) available from the Vancouver Public Library

Return to Page 1

Suggested books on bereavement for Children and Parents:

- Healing a Child's Grieving Heart - 100 Practical Ideas for Families, Friends and Caregivers *(VPL)
  Alan D. Wolfelt, 2001
  The author provides helpful advice when family and friends often find it tough to know how to react to a grieving child.

- Help for the Hard Times: Getting Through Loss
  Earl Hipp, 1995
  For Teenagers. An informal presentation - combining lots of information, suggestions and resources - makes this book very appealing to teens.

- How it Feels when a Parent Dies *(VPL)
  Jill Krementz, editor, 1981
  8 years old to teenagers. Eighteen young people ranging in age from seven to seventeen discuss the questions, fears, and bereavement they experienced when a parent died

- Learning to Say Goodbye when a Parent Dies *(VPL)
  Eda LeShan, 1976
  For the whole family, adults and children. Written in simple direct language, to help open communication about questions, fears and stages of mourning.

- Straight Talk about Death for Teenagers: How to Cope with the Death of Someone You Love
  Earl Grollman, 1993
  For teenagers. Just a few incisive lines on each page. Speaks directly to teens. Includes a journal section for writing about memories and feelings.

- Talking about Death: A Dialogue between Parent and Child *(VPL)
  Earl Grollman, 1990
  Preschool to age 10, with parents. Begins with children's illustrated read-along section, followed by a parent's guide to support talking about feelings. Includes lists of resources.

- The Grieving Child: A Parent's Guide *(VPL)
  Helen Fitzgerald & Elisabeth Kubler-Ross, 1992
  For parents only. Explains how children of different ages deal with death and grief.

- The Three Birds: A Story for Children about the Loss of a Loved One (available at chapter.ca)
  Sandra Irelend Marinus van den Berg, 1994
  For preschool to age 7. A popular well illustrated book.

- When Dinosaurs Die: A Guide to Understanding Death *(VPL)
  Laurie Krasny Brown & Marc Brown, 1996
  Preschool to age 8. Addresses children's fears and curiosity directly. Answers children's very basic questions such as: "What does it mean to be dead?" Illustrated.

*(VPL) available from the Vancouver Public Library

Return to Page 1

For more copies, go online at **http://vch.eduhealth.ca** or email **phem@vch.ca** and quote Catalogue No. **GV.300.W574**

www.vch.ca

Vancouver CoastalHealth
Promoting wellness. Ensuring care.

Return to Page 1

Print

Preparing for the Death of a Loved One

Information for Patients & Visitors

Providence HEALTH CARE
How you want to be treated.

North Shore, Sea to Sky,
Sunshine Coast, Powell River,
Richmond and Vancouver

Return to Page 1

This booklet is provided to help you to know what to expect when your loved one is dying. It may help you to respond in ways that will help you and your loved one accomplish this transition with understanding and comfort. We know this is a difficult time for you and encourage you to take time to care for yourself and accept the support of friends, family and staff. The team caring for your loved one is also here to support you.

Physical, emotional, spiritual and mental changes are occurring as a person enters the final stages of life.

Physical

The body goes through a number of changes in the final process of shutting down all physical systems. These physical changes are normal and natural, and are ways in which the body prepares itself to stop functioning. The team may be giving your loved one medication to treat pain or shortness of breath. Morphine-like medications are safe to use for this and do not cause death to happen any sooner. They keep your loved one comfortable as they die from their disease.

Emotional

Some people may wish to renew or heal significant relationships. Be prepared to listen and encourage visits from those your loved one wishes to see.

Some people feel they need their family's permission to let go after struggling with an illness. A dying person will sometimes try to hold on, even though it may bring discomfort, in order to be assured that those left behind will be all right. If this may be a concern, reassuring your loved one that they can let go, and not be worried about you may be a significant gift to them.

Return to Page 1

Spiritual

Each one of us has inner spiritual strength that helps us to cope with losses, changes and suffering. These inner resources may come from being part of a spiritual or religious community, from nature, relationships or other things that give value to our life. You may be helpful to your loved one by helping them to access their inner strength. This may mean helping to arrange spiritual or religious practices, visits of friends, family or by listening to your loved one. For some people, being able to talk about important events in their life, the people they have loved, the things they have done as well what they hope for the people they love can help spiritual healing.

Your own inner resources can also be helpful to you at this time as you try to cope with seeing one you love at the end of his or her life. Make sure you take time to care for yourself as you go through this journey with your loved one.

Saying Good-Bye

When death is imminent, it is the time to say good-bye in personal ways. It may be helpful to just lay in bed with your loved one, hold a hand, and/or say what you need to say. Tears are a natural part of saying good-bye. They do not need to be hidden or apologized for, as they are expressions of love.

The following signs and symptoms of impending death will help you understand the natural processes that may happen, and how to respond appropriately. Each person is unique, hence not all these signs/symptoms occur, nor will they be in the same sequence.

It is hard to predict when a person will die and sometimes it seems that the person is lingering on. Death, like giving birth, is not a completely predictable event.

Fluid & Food Decrease

Food is important in all cultures and preparing food is often a way of showing love for someone. However, at the end of life, there may be a decrease in appetite and thirst, with your loved one wanting little or no food or fluid. The body does not need much energy at this time and the digestive system cannot process much food or fluids. Do not force him/her into eating or drinking as it will not change what is happening and can cause emotional upset, and/or physical discomfort. When the body does not desire food or fluids an IV is not necessary to keep the person comfortable and can often lead to fluid overload and lung congestion. Lack of fluids in the body is not uncomfortable if the mouth is kept moist.

In the same way, feeding through a tube in the nose or into the stomach does not alter the dying process. There are side effects to tube feeding including lung infection from food particles entering into the lungs as well as discomfort from the feeds. If you have concerns about your loved one's eating and drinking, please speak with the team involved in their care.

Return to Page 1

What you can do:

Small chips of ice, frozen juices/ popsicles may be refreshing in the mouth. Be aware of decrease in swallowing ability. Reflexes needed to swallow may be sluggish, so do not give fluids if the person coughs soon after they swallow.
The person's body lets him/her know when it no longer desires or cannot tolerate food or liquids. The loss of this desire is a signal that the person is getting ready to die.
Use moisturized swabs or a water soluble lubricant to keep the mouth and lips moist and hydrated if your loved one no longer is able to swallow.

Decreased Socialization

Some people like to have people with them all the time. Others may want to be alone or with just one or very few people. This is natural as he/she will be weak and fatigued and not able to socialize much. You may feel that the person is lonely and needs to be more involved in life. However, do not feel that you must always talk, sometimes it is good just to sit together quietly.

What you can do:

Reassure the person that it is okay to rest if they do not wish to talk, or they do not respond to your words.

Sleeping

The person may spend an increasing amount of time sleeping and appear to be uncommunicative, unresponsive, and at times difficult to arouse. This normal change is due in part to changes in the metabolism of the body and brain. Sit with and hold his/her hand, speak softly and naturally. You may wish to spend time when he/she is most alert but just being there whenever you can is fine.

What you can do:

Speak directly and normally, even though there may be no response. **Never** assume that the person cannot hear or feel, as we do not know how well the senses function at this stage of life.

Restlessness

The person may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens partly due to the decrease in circulation to the brain, and metabolic changes. Do not be alarmed, and do not interfere or try to restrain such motions. If you believe your loved one is restless for a reason such as pain, shortness of breath or an uncomfortable position please let the team caring for your loved one know so that they can help

What you can do:

To have a calming effect, speak in a quiet, natural way, lightly massage the hand or forehead, read to the person or play soothing music.

Return to Page 1

Confusion

The person may seem confused about time, place and identity of people surrounding him/her, including close familiar people. The team caring for your loved one will try to identify causes of confusion that can be fixed but often this can occur as a natural part of the process of dying.

What you can do:

Identify yourself by name before you speak. Speak softly, clearly and simply when communicating something important for your loved one's comfort such as, "It's time to take your medication so you won't begin to hurt". Do not feel that you must correct their confusion as this can increase the distress of your loved one.

Urine Decrease

The person's urine output normally decreases and may become tea-colored, and concentrated. This is due to the decrease in the intake of fluids as well as decreased circulation through the kidneys. A nurse can determine if there is a need to insert a catheter.

Breathing Pattern Change

The person's regular breathing pattern may change close to death. A particular pattern consists of breathing irregularly with shallow respirations, or periods of no breathing for 5 to 30 seconds, followed by a deep breath. Sometimes there is a moaning-like sound on exhaling. This is not distress, but the sound of air passing over relaxed vocal chords. These patterns are very common and indicate a decreased circulation in the part of the brain that controls the breathing.

What you can do:

Elevating the head and/or turning onto the side may change the breathing pattern but this is not necessary as it is a normal part of dying. Hold your loved one's hand. Speak gently and reassuringly.

Return to Page 1

Congestion

The person may develop gurgling sounds coming from the chest that sound like a percolator. These sounds are from mucous that would normally be cleared if your loved one were more alert and awake. Sometimes these sounds become very loud and they can be very distressing to hear. Watch your loved one closely and note that they are usually unaware of their bodily processes. It is often harder for you to watch than it is for the patient. Trying to suction out the congestion is uncomfortable and most often not successful. Medication that reduces the secretions can be given.

What you can do:

Raise the head of the bed so the secretions stay lower and don't stimulate the gag reflex. Elevating the head and/or turning onto the side may reduce the gurgling sounds. Hold your loved one's hand. Speak gently and reassuringly.

Color Changes

The person's arms and legs may become cold, hot or discoloured. The underside of the body may become discoloured as circulation decreases. This is a natural change indicating that the circulation is conserving to the core to support the most vital organs. Irregular temperatures can occur as a result of the brain sending unclear messages.

What you can do:

Keep your loved one warm if they appear cold, but do not use an electric blanket. If the person continually removes the covers, then allow them just a light sheet or use a fan to cool them.

At the Time of Death

- breathing ceases
- heartbeat ceases
- the person cannot be aroused
- the eyelids may be partially open with the eyes in a fixed stare
- the mouth may fall open as the jaw relaxes

The body of your loved one is still soft and warm for some time. You can touch their body and hold them if this is what you wish to do. Some people like to stay with the body for some time after death and others do not. Spend as much time with the body of your loved one as you need.

Some people have spiritual or cultural traditions that are done after death. If your loved one dies in a healthcare facility please let the staff know ahead so we can be more helpful to you.

You will need to speak to a funeral director within the first day after your loved one has died, but it does not have to be done immediately. It is always helpful if you have made arrangements with a funeral home prior to the death so that you know who to call, especially at a time when you are feeling stressed.

Return to Page 1

This information is provided so the transition from life to death may be as natural as possible.

Please ask your care team any questions you may have.

Adapted with permission by the Neighbourhood Visiting Nurses Association of West Chester, Pennsylvania, USA for use at Vancouver Coastal Health and Providence Health Care.

For more copies, go online at **http://vch.eduhealth.ca** or email **phem@vch.ca** and quote Catalogue No. **GV.100.P919**

Vancouver CoastalHealth
Promoting wellness. Ensuring care.

Return to Page 1

Print

如何預備親人即將離世

Preparing for the Death of a Loved One

病人及親友參考資料

Information for Patients & Visitors

North Shore, Sea to Sky,
Sunshine Coast, Powell River,
Richmond and Vancouver

Return to Page 1

這小冊子是為面臨親人將要離世的你而準備的。它可幫助你和你的親人了解更多，舒適地走完人生旅程。我們明白這是一個很困難的時刻，因此我們建議你要花點時間照顧自己，接受朋友、家人及同事的幫助。負責照顧病人的護理人員也會給予協助。

Return to Page 1

當人進入人生最後階段，身體、情緒、靈性及心理各方面都會有所改變。

身體改變

步入生命最後的階段，身體會經歷一連串改變。這些都是為了預備身體功能即將停止的正常改變。護理人員可能會為親人提供止痛及減少氣喘的藥物。這些嗎啡類的藥物是安全的，並不會加快病人的衰竭或者死亡過程，卻可以令你的親人在最後的日子過得舒服一點。

情緒

有些人希望在離世前重建或修補一段重要的關係，因此要細聽親人的需要，並鼓勵親人想見的人前來探訪。

有時候病人感覺需要家人的「准許」，才可放棄與疾病搏鬥。有時候病人會不肯放棄，甚至痛苦地堅持下去，因為不放心留下家人。如果有這樣的情況，安慰他/她可以安心離去是你能給他/她最好的禮物。

Return to Page 1

靈性

每個人都有一種內心的力量，幫助我們面對所失去的，以及改變和苦楚。這種力量有時是來自所屬的宗教團體，人際關係，或是其他令你生命有價值的東西。你也許可以幫助你的親人找到內在的力量，例如安排宗教的活動，朋友及家人的探望，或是聆聽他的說話。對某些人來說，可以與人傾訴關於生命中重要的事情，關於他們所愛的人、所做過的事情，或對所愛的人的期望，都會帶來心靈的醫治。

當你眼見親人快要離世的時候，你的內心力量也會成為你的支持。緊記在你陪伴親人走完最後路程的同時，也要花時間照顧自己。

說再見

當親人快要離世，便是以個人方式道別的時候。你可以在床上與親人手牽著手，及/或傾訴一些你想說的說話。道別時流淚是很自然的，所以不需隱藏或感到難為情，因為這是愛的流露。

以下是一些當人快離世的時候的徵兆和症狀，幫助你明白這個自然的過程，並如何作出適當反應。因為每個人都是不一樣的，所以並非所有徵兆/症狀都會出現，或者按一定的次序出現。

Return to Page 1

減少飲食

食物在每個文化都很重要，而為他人預備食物往往是表達愛的方法之一。但當人在將要離世時，食慾及口渴會減少，因此親人或祇需要少量食物及飲料水份，甚至不想吃喝。這是由於身體不再需要太多能量。因此不要強迫他們吃、喝甚麼，因為飲食不能改變現狀，祇會增加親人的心理不安及/或身體不適。維持正常的飲食往往是不可能的，而且靜脈注射也不一定可以令親人感覺更舒服，甚至造成體內水份過多及肺積水。如果能維持口腔濕潤，體內缺水未必會造成不適。

而且，利用鼻管及胃管餵食，亦不會改變死亡的過程。相對地，管子餵食有其副作用，例如食物或會進入肺部造成感染，以及餵管本身會造成病人不舒服。如果你對親人的飲食有疑問，請與負責的護理人員商量。

你可以做的事情：

小片的冰塊、冰凍的果汁/冰條可以令口腔感覺清新。要留意親人吞食能力的減退。他們的吞食反應可能會變得遲頓，因此當病人吞嚥後開始咳嗽，便要立即停止給予水份。他們的身體會讓他們知道甚麼時候不再要或不能吃喝。失去食慾是人快要離世的訊號。如果你的親人不能再吞嚥，可以用濕棉花棒或水溶的潤滑劑去保持病人口腔及嘴唇濕潤。

Return to Page 1

減少與人社交

有的人時常希望有很多人陪伴左右，有的則寧願獨處，或祇有一位或少量友好陪伴。這都是正常的，因為當親人的身體軟弱及疲倦時，他/她就不能跟以往一樣與人社交。你可能會覺得他很孤單需要多參與活動。總之，不要認為你必須找話題，有時候靜靜地陪伴病人左右是很好的。

你可以做的事情:

告訴親人如果他們不想談話可以休息，他們亦不一定要回應你說的話。

睡覺

親人可能會增加很多睡覺時間，而且表現出無法溝通，沒有反應的現象。

這改變是正常的，因為這是腦部與身體的新陳代謝改變所帶來的轉變。你可以坐在親人的旁邊，握著他/她的手，輕輕及自然地與他/她交談。嘗試在親人最清醒的時候與他/她一起。有時候，伴隨左右比幫他/她做事情更重要。

Return to Page 1

你可以做的事情：

向他/她直接及正常地說話，即使對方沒有反應。千萬不要假設他/她聽不到或感受不到你說的話，因為我們不清楚在這個階段病人的感覺器官如何運作。

煩躁不安
Restlessness

病人可能會重複不停地做某些動作，例如整理床舖或衣服。部分原因可能是由於腦部血液循環減少，或新陳代謝改變所致。不要緊張，也不需干預或制止這些舉動。如果你認為你的親人表現不安，是由於痛楚、氣喘或不舒服的姿勢所致，請通知護理人員，讓他們協助。

你可以做的事情：

柔聲及自然的對親人說話，溫柔地按摩親人的手及前額，讀書給他/她聽或播放柔和的音樂都可以幫助親人鎮定下來。

Return to Page 1

迷惘

親人可能對時間、地點及周圍的人感到迷惘，即使是近親。護理人員可嘗試找出病人感覺困惑的原因，並協助處理，但這往往是死亡過程的自然現象。

你可以做的事情：

在說話前先說出你是誰，不要讓親人去猜。在告訴親人一些可以令他/她更舒適的事情時，要輕聲、清楚及誠懇地說出來，例如「是時候服藥了」。同時要解釋原因，例如「這是好的，是讓你不會感覺痛楚的」。

排尿減少

病人排尿會自然減少，或有茶色、濃度極高的尿液。這是由於減少飲水，以及腎臟的水份循環減少的原因。護士會決定他/她是否需要插尿管。

Return to Page 1

呼吸方式的改變

快離世的時候，親人的呼吸方式可能會改變。呼吸會變得不穩定:淺且急促的呼吸。有時或會停止呼吸5-30秒，然後才深深吸一口氣。有時候呼氣的聲音有點嗚咽似的。這並非代表他/她在受苦，而是空氣通過放鬆的氣管所發出的聲音。這些都是正常的，並顯示腦部控制呼吸的部份的血液循環減少了。

你可以做的事情:

你可以嘗試托高病人的頭，及/或把頭轉向一邊，也許改變他/她的呼吸方式。但這種方法幫助不大，因為這是離世前的正常情況。你可以握著他/她的手，在其耳邊溫柔說安撫的說話。

Return to Page 1

氣管阻塞

親人的胸部可能會發出咯咯聲，就像過濾器的聲音。有時候這些聲音會變得很大，令聽的人感到很難受。但如果你小心觀察你的親人，你或會發覺他/她並未留意到身體這方面的改變。通常旁觀者會比當事人更難受。這些阻塞是來自鼻腔、口腔及喉嚨的分泌物造成，如果要強行抽吸反而會造成不適，亦往往不奏效。醫生可以用處方藥物減少分泌物。

你可以做的事情：

你可以嘗試抬高親人的頭，來阻止分泌物倒流，和作嘔反應。托高親人的頭並把頭轉向一邊，或能減少咯咯聲。你可以握著他/她的手，在其耳邊溫柔說安撫的說話。

膚色改變

親人的手腳也許會轉冷、轉熱或變色。下半身可能因為血液循環減少而變色。這都是正常的，代表身體把血液輸送到最重要的器官。不正常的體溫可能是由於腦部輸出不明確的訊息所致。

你可以做的事情：

如果病人看來感到寒冷，可以幫他/她取暖，但不要使用電毯子。如果親人會不停把被單移開，便要幫他們換成薄被單或使用電風扇散熱。

Return to Page 1

去世的時候

- 呼吸會停止
- 心跳會停止
- 親人不再被喚醒
- 眼皮或會稍微張開，但目光卻是呆滯不動
- 下巴會放鬆，所以嘴巴可能張開

親人的身體會持續柔軟及溫暖一陣子。如果想的話，你可以抱著他們。有些人希望多留一陣子，有些人不願意。你可依照自己的需要，決定停留的時間。

有些人會希望以某種宗教儀式或文化傳統下葬，如果你的親人在醫療機構內離世，可預先通知工作人員有關安排，好讓他們加以協助。

你需要在親人離世後的一天之內與殯儀館人員聯絡，但無需立即進行下葬。如果你在親人離世前已預先與殯儀館人員打點安排葬禮的事宜，即使在傷痛中你也知道要聯絡誰。

Return to Page 1

我們提供這份資料，是要讓親人離世的過程
自然及詳和。

如有任何問題，請與護理人員聯絡。

獲美國賓州 Neighbourhood Visiting Nurses Association of Western Chester **授權使用**

Adapted with permission by the Neighbourhood Visiting Nurses Association of Western Chester, Pennsylvania, USA for use at Vancouver Coastal Health.

For more copies, go online at **http://vch.eduhealth.ca** or email **phem@vch.ca** and quote Catalogue No. **GV.100.P919.CN**

這文件內的資料，由醫療衛生人員特別為個別病人提供。

www.vch.ca

Vancouver CoastalHealth
Promoting wellness. Ensuring care.

Return to Page 1

Punjabi

Print

ਆਪਣੇ ਕਿਸੇ ਪਿਆਰੇ ਦੀ ਮੌਤ ਲਈ ਤਿਆਰੀ ਕਰਨਾ

ਮਰੀਜ਼ਾਂ ਅਤੇ ਦੇਖਣ ਆਉਣ ਵਾਲਿਆਂ ਲਈ ਜਾਣਕਾਰੀ

Preparing for the Death of a Loved One

Information for Patients & Visitors

Providence HEALTH CARE
How you want to be treated.

North Shore, Sea to Sky,
Sunshine Coast, Powell River,
Richmond and Vancouver

Return to Page 1

ਇਹ ਕਿਤਾਬਚਾ ਇਹ ਜਾਣਨ ਵਿਚ ਤੁਹਾਡੀ ਮਦਦ ਕਰਨ ਲਈ ਤਿਆਰ ਕੀਤਾ ਗਿਆ ਹੈ ਕਿ ਜਦੋਂ ਤੁਹਾਡਾ ਪਿਆਰ ਮਰ ਰਿਹਾ ਹੁੰਦਾ ਹੈ ਤਾਂ ਕੀ ਉਮੀਦ ਰੱਖਣੀ ਹੈ। ਇਹ ਤੁਹਾਡੀ ਉਨ੍ਹਾਂ ਤਰੀਕਿਆਂ ਨਾਲ ਹੁੰਗਾਰਾ ਭਰਨ ਵਿਚ ਮਦਦ ਕਰ ਸਕਦਾ ਹੈ ਜਿਹੜੇ ਤੁਹਾਡੀ ਅਤੇ ਤੁਹਾਡੇ ਪਿਆਰੇ ਦੀ, ਇਸ ਤਬਦੀਲੀ ਨੂੰ ਸਮਝ ਅਤੇ ਆਰਾਮ ਨਾਲ ਪ੍ਰਾਪਤ ਕਰਨ ਵਿਚ ਮਦਦ ਕਰਨਗੇ। ਸਾਨੂੰ ਪਤਾ ਹੈ ਕਿ ਇਹ ਸਮਾਂ ਤੁਹਾਡੇ ਲਈ ਬਹੁਤ ਔਖਾ ਸਮਾਂ ਹੈ ਅਤੇ ਅਸੀਂ ਤੁਹਾਨੂੰ ਉਤਸ਼ਾਹ ਦਿੰਦੇ ਹਾਂ ਕਿ ਤੁਸੀਂ ਆਪਣਾ ਖਿਆਲ ਰੱਖਣ ਲਈ ਸਮਾਂ ਕੱਢੋ ਅਤੇ ਦੋਸਤਾਂ, ਪਰਿਵਾਰ ਅਤੇ ਸਟਾਫ ਦੀ ਮਦਦ ਪ੍ਰਵਾਨ ਕਰੋ। ਤੁਹਾਡੇ ਪਿਆਰੇ ਦੀ ਸੰਭਾਲ ਕਰ ਰਹੀ ਟੀਮ ਵੀ ਤੁਹਾਡੀ ਮਦਦ ਲਈ ਮੌਜੂਦ ਹੈ।

Return to Page 1

ਜਦੋਂ ਕੋਈ ਵਿਅਕਤੀ ਜ਼ਿੰਦਗੀ ਦੇ ਆਖਰੀ ਪੜਾਵਾਂ ਵਿਚ ਦਾਖਲ ਹੁੰਦਾ ਹੈ ਤਾਂ ਸਰੀਰਕ, ਜਜ਼ਬਾਤੀ, ਅਧਿਆਤਮਿਕ ਅਤੇ ਦਿਮਾਗੀ ਤਬਦੀਲੀਆਂ ਵਾਪਰ ਰਹੀਆਂ ਹੁੰਦੀਆਂ ਹਨ।

ਸਰੀਰਕ

ਸਾਰੇ ਸਰੀਰਕ ਸਿਸਟਮਾਂ ਨੂੰ ਬੰਦ ਕਰਨ ਦੇ ਅੰਤਿਮ ਕਾਰਜ ਵਿਚ ਸਰੀਰ ਕਈ ਤਬਦੀਲੀਆਂ ਵਿਚ ਦੀ ਲੰਘਦਾ ਹੈ। ਇਹ ਸਰੀਰਕ ਤਬਦੀਲੀਆਂ ਆਮ ਅਤੇ ਕੁਦਰਤੀ ਹਨ ਅਤੇ ਉਹ ਤਰੀਕੇ ਹਨ ਜਿਨ੍ਹਾਂ ਰਾਹੀਂ ਸਰੀਰ ਕੰਮ ਕਰਨਾ ਬੰਦ ਕਰਨ ਲਈ ਆਪਣੇ ਆਪ ਨੂੰ ਤਿਆਰ ਕਰਦਾ ਹੈ। ਟੀਮ ਦਰਦ ਜਾਂ ਸਾਹ ਚੜ੍ਹਨ ਨੂੰ ਘੱਟ ਕਰਨ ਲਈ ਤੁਹਾਡੇ ਪਿਆਰੇ ਨੂੰ ਦਵਾਈ ਦੇ ਸਕਦੀ ਹੈ। ਇਸ ਲਈ ਮੌਰਫੀਨ ਵਰਗੀਆਂ ਦਵਾਈਆਂ ਵਰਤਣ ਲਈ ਸੁਰੱਖਿਅਤ ਹਨ ਅਤੇ ਇਨ੍ਹਾਂ ਨਾਲ ਮੌਤ ਪਹਿਲਾਂ ਨਹੀਂ ਹੋ ਜਾਂਦੀ। ਉਹ ਤੁਹਾਡੇ ਪਿਆਰੇ ਨੂੰ ਆਪਣੀ ਬੀਮਾਰੀ ਕਾਰਨ ਮਰਨ ਸਮੇਂ ਆਰਾਮਦੇਹ ਰੱਖਦੀਆਂ ਹਨ।

ਜਜ਼ਬਾਤੀ

ਕੁਝ ਲੋਕ ਨੇੜਲੇ ਸਬੰਧਾਂ ਨੂੰ ਨਵਿਆਉਣ ਜਾਂ ਠੀਕ ਕਰਨਾ ਚਾਹੁੰਦੇ ਹੋ ਸਕਦੇ ਹਨ। ਸੁਣਨ ਲਈ ਤਿਆਰ ਰਹੋ ਅਤੇ ਉਨ੍ਹਾਂ ਲੋਕਾਂ ਨੂੰ ਮਿਲਣ ਆਉਣ ਲਈ ਉਤਸ਼ਾਹ ਦਿਉ ਜਿਨ੍ਹਾਂ ਨੂੰ ਤੁਹਾਡਾ ਪਿਆਰਾ ਦੇਖਣਾ ਚਾਹੁੰਦਾ ਹੈ।

ਕੁਝ ਲੋਕ ਇਸ ਤਰ੍ਹਾਂ ਮਹਿਸੂਸ ਕਰਦੇ ਹਨ ਕਿ ਬੀਮਾਰੀ ਨਾਲ ਜੱਦੋਜਹਿਦ ਕਰਨ ਤੋਂ ਬਾਅਦ ਆਪਣਾ ਸਰੀਰ ਛੱਡਣ ਲਈ ਉਨ੍ਹਾਂ ਨੂੰ ਆਪਣਾ ਪਰਿਵਾਰ ਦੀ ਆਗਿਆ ਦੀ ਲੋੜ ਹੁੰਦੀ ਹੈ। ਮਰ ਰਿਹਾ ਵਿਅਕਤੀ ਕਦੇ ਕਦੇ ਜਿਊਂਦਾ ਰਹਿਣ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰਦਾ ਹੈ ਭਾਵੇਂ ਕਿ ਇਸ ਨਾਲ ਉਸ ਨੂੰ ਬੇਆਰਾਮੀ ਹੁੰਦੀ ਹੋਵੇ ਤਾਂ ਜੋ ਉਸ ਨੂੰ ਯਕੀਨ ਹੋ ਜਾਵੇ ਕਿ ਪਿੱਛੇ ਰਹਿ ਗਏ ਲੋਕ ਠੀਕ ਰਹਿਣਗੇ। ਜੇ ਕੋਈ ਅਜਿਹਾ ਸਰੋਕਾਰ ਹੈ ਤਾਂ ਆਪਣੇ ਪਿਆਰੇ ਨੂੰ ਇਹ ਯਕੀਨ ਦਵਾਉਣਾ ਕਿ ਉਹ ਜਾ ਸਕਦੇ ਹਨ ਅਤੇ ਤੁਹਾਡੇ ਬਾਰੇ ਫਿਕਰ ਨਾ ਕਰਨ, ਉਨ੍ਹਾਂ ਲਈ ਇਕ ਮਹੱਤਵਪੂਰਨ ਤੋਹਫਾ ਹੋ ਸਕਦਾ ਹੈ।

Return to Page 1

ਅਧਿਆਤਮਿਕ

ਸਾਡੇ ਹਰ ਦੇ ਅੰਦਰ ਇਕ ਅਧਿਆਤਮਿਕ ਤਾਕਤ ਹੁੰਦੀ ਹੈ ਜਿਹੜੀ ਨੁਕਸਾਨਾਂ, ਤਬਦੀਲੀਆਂ ਅਤੇ ਦੁੱਖ ਝੱਲਣ ਵਿਚ ਸਾਡੀ ਮਦਦ ਕਰਦੀ ਹੈ। ਇਹ ਅੰਦਰੂਨੀ ਵਸੀਲੇ ਕਿਸੇ ਅਧਿਆਤਮਿਕ ਜਾਂ ਧਾਰਮਿਕ ਕਮਿਉਨਟੀ ਦਾ ਹਿੱਸਾ ਹੋਣ ਕਰਕੇ ਹੋ ਸਕਦੇ ਹਨ, ਜਾਂ ਕੁਦਰਤ, ਰਿਸ਼ਤਿਆਂ ਜਾਂ ਹੋਰ ਅਜਿਹੀਆਂ ਚੀਜ਼ਾਂ ਕਰਕੇ ਹੋ ਸਕਦੇ ਹਨ ਜਿਹੜੇ ਸਾਡੀ ਜ਼ਿੰਦਗੀ ਨੂੰ ਮਹੱਤਵ ਦਿੰਦੇ ਹਨ। ਆਪਣੀ ਅੰਦਰੂਨੀ ਤਾਕਤ ਤੱਕ ਪਹੁੰਚ ਕਰਨ ਵਿਚ ਆਪਣੇ ਪਿਆਰੇ ਦੀ ਮਦਦ ਕਰਕੇ ਤੁਸੀਂ ਮਦਦਗਾਰ ਬਣ ਸਕਦੇ ਹੋ। ਇਸ ਦਾ ਮਤਲਬ, ਅਧਿਆਤਮਿਕ ਜਾਂ ਧਾਰਮਿਕ ਰੀਤੀਆਂ, ਦੋਸਤਾਂ, ਪਰਿਵਾਰ ਦੀਆਂ ਫੇਰੀਆਂ ਦਾ ਪ੍ਰਬੰਧ ਕਰਨਾ ਜਾਂ ਆਪਣੇ ਪਿਆਰੇ ਨੂੰ ਸੁਣਨਾ ਹੋ ਸਕਦਾ ਹੈ। ਕੁਝ ਲੋਕਾਂ ਲਈ, ਆਪਣੀ ਜ਼ਿੰਦਗੀ ਦੀਆਂ ਮਹੱਤਵਪੂਰਨ ਘਟਨਾਵਾਂ, ਜਿਨ੍ਹਾਂ ਲੋਕਾਂ ਨੂੰ ਉਨ੍ਹਾਂ ਨੇ ਪਿਆਰ ਕੀਤਾ, ਜਿਹੜੀਆਂ ਚੀਜ਼ਾਂ ਉਨ੍ਹਾਂ ਨੇ ਕੀਤੀਆਂ ਅਤੇ ਇਸ ਦੇ ਨਾਲ ਨਾਲ ਆਪਣੇ ਪਿਆਰੇ ਲੋਕਾਂ ਬਾਰੇ ਉਹ ਕੀ ਆਸ ਰੱਖਦੇ ਹਨ, ਉਸ ਬਾਰੇ ਗੱਲ ਕਰਨ ਦੇ ਯੋਗ ਹੋਣਾ ਅਧਿਆਤਮਿਕ ਸ਼ਾਂਤੀ ਵਿਚ ਮਦਦ ਕਰ ਸਕਦੀਆਂ ਹਨ।

ਇਸ ਵੇਲੇ ਤੁਹਾਡੇ ਆਪਣੇ ਅੰਦਰੂਨੀ ਵਸੀਲੇ ਤੁਹਾਡੀ ਵੀ ਮਦਦ ਕਰ ਸਕਦੇ ਹਨ ਜਦੋਂ ਤੁਸੀਂ ਆਪਣੇ ਪਿਆਰੇ ਨੂੰ ਆਪਣੀ ਜ਼ਿੰਦਗੀ ਦੇ ਅੰਤ 'ਤੇ ਦੇਖਣ ਦੇ ਦੁੱਖ ਨਾਲ ਸਿੱਝਣ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰਦੇ ਹੋ। ਆਪਣੇ ਪਿਆਰੇ ਨਾਲ ਇਸ ਸਫਰ ਵਿਚ ਦੀ ਗੁਜ਼ਰਨ ਵੇਲੇ ਆਪਣਾ ਖਿਆਲ ਰੱਖਣਾ ਯਾਦ ਰੱਖੋ।

ਅਲਵਿਦਾ ਕਹਿਣਾ

ਜਦੋਂ ਮੌਤ ਅਟੱਲ ਹੁੰਦੀ ਹੈ ਤਾਂ ਇਹ ਸਮਾਂ ਨਿੱਜੀ ਤਰੀਕਿਆਂ ਨਾਲ ਅਲਵਿਦਾ ਕਹਿਣ ਦਾ ਹੁੰਦਾ ਹੈ। ਆਪਣੇ ਪਿਆਰੇ ਨਾਲ ਬੈੱਡ ਵਿਚ ਲੰਮੇ ਪੈਣਾ, ਹੱਥ ਫੜਣਾ, ਅਤੇ/ਜਾਂ ਦਿਲ ਦੀ ਗੱਲ ਕਹਿਣਾ ਮਦਦ ਕਰਨ ਵਾਲਾ ਹੋ ਸਕਦਾ ਹੈ। ਹੰਝੂ ਅਲਵਿਦਾ ਕਹਿਣ ਦਾ ਇਕ ਕੁਦਰਤੀ ਹਿੱਸਾ ਹੈ। ਉਹ ਲੁਕਾਉਣ ਦੀ ਲੋੜ ਨਹੀਂ ਹੈ ਜਾਂ ਉਨ੍ਹਾਂ ਲਈ ਮਾਫੀ ਮੰਗੇ ਜਾਣ ਦੀ ਲੋੜ ਨਹੀਂ ਹੈ ਕਿਉਂਕਿ ਇਹ ਪਿਆਰ ਦਾ ਪ੍ਰਗਟਾਵਾ ਹਨ।

ਮੌਤ ਦੇ ਨੇੜੇ ਹੋਣ ਦੀਆਂ ਅੱਗੇ ਲਿਖੀਆਂ ਨਿਸ਼ਾਨੀਆਂ ਅਤੇ ਲੱਛਣ, ਉਨ੍ਹਾਂ ਕੁਦਰਤੀ ਕਾਰਜਾਂ ਨੂੰ ਸਮਝਣ ਵਿਚ ਤੁਹਾਡੀ ਮਦਦ ਕਰਨਗੇ ਜਿਹੜੇ ਵਾਪਰ ਸਕਦੇ ਹਨ ਅਤੇ ਤੁਹਾਨੂੰ ਇਹ ਦੱਸਣਗੇ ਕਿ ਠੀਕ ਤਰੀਕੇ ਨਾਲ ਹੁੰਗਾਰਾ ਕਿਵੇਂ ਭਰਨਾ ਹੈ। ਹਰ ਕੋਈ ਵਿਲੱਖਣ ਹੈ, ਇਸ ਕਰਕੇ ਇਹ ਸਾਰੀਆਂ ਨਿਸ਼ਾਨੀਆਂ/ਲੱਛਣ ਨਹੀਂ ਵਾਪਰਦੇ, ਅਤੇ ਨਾ ਹੀ ਇਹ ਇੱਕੋ ਤਰਤੀਬ ਵਿਚ ਵਾਪਰਨਗੇ।

Return to Page 1

ਇਹ ਭਵਿੱਖਬਾਣੀ ਕਰਨਾ ਔਖਾ ਹੈ ਕਿ ਵਿਅਕਤੀ ਦੀ ਮੌਤ ਕਦੋਂ ਹੋਵੇਗੀ ਅਤੇ ਕਦੇ ਕਦੇ ਇਸ ਤਰ੍ਹਾਂ ਲੱਗਦਾ ਹੈ ਕਿ ਉਹ ਵਿਅਕਤੀ ਸਿਰਫ ਜ਼ਿੰਦਗੀ ਨਾਲ ਚਿੰਬੜਿਆ ਹੋਇਆ ਹੈ। ਜਨਮ ਵਾਂਗ ਮੌਤ, ਪੂਰੀ ਤਰ੍ਹਾਂ ਭਵਿੱਖਬਾਣੀ ਕਰਨ ਯੋਗ ਨਹੀਂ ਹੈ।

ਪੀਣ ਅਤੇ ਖਾਣ ਵਿਚ ਕਮੀ

ਖਾਣਾ ਸਾਰੇ ਸਭਿਆਚਾਰਾਂ ਵਿਚ ਮਹੱਤਵਪੂਰਨ ਹੈ ਅਤੇ ਖਾਣਾ ਤਿਆਰ ਕਰਨਾ ਅਕਸਰ ਕਿਸੇ ਲਈ ਪਿਆਰ ਦਿਖਾਉਣ ਦਾ ਇਕ ਤਰੀਕਾ ਹੈ। ਪਰ ਜ਼ਿੰਦਗੀ ਦੇ ਅੰਤ 'ਤੇ ਭੁੱਖ ਅਤੇ ਪਿਆਸ ਵਿਚ ਕਮੀ ਆ ਸਕਦੀ ਹੈ ਅਤੇ ਤੁਹਾਡਾ ਪਿਆਰਾ ਬਹੁਤ ਥੋੜ੍ਹਾ ਜਾਂ ਬਿਲਕੁਲ ਕੋਈ ਖਾਣਾ ਜਾਂ ਪੀਣਾ ਨਾ ਚਾਹੁੰਦਾ ਹੋਵੇ। ਇਸ ਸਮੇਂ ਸਰੀਰ ਨੂੰ ਬਹੁਤੀ ਤਾਕਤ ਦੀ ਲੋੜ ਨਹੀਂ ਹੁੰਦੀ ਹੈ ਅਤੇ ਖਾਣਾ ਪਚਾਉਣ ਦਾ ਸਿਸਟਮ ਬਹੁਤਾ ਖਾਣਾ ਜਾਂ ਪੀਣਾ ਪਚਾ ਨਹੀਂ ਸਕਦਾ। ਉਸ ਨੂੰ ਖਾਣ ਜਾਂ ਪੀਣ ਲਈ ਮਜ਼ਬੂਰ ਨਾ ਕਰੋ ਕਿਉਂਕਿ ਇਸ ਨਾਲ ਜੋ ਹੋ ਰਿਹਾ ਹੈ ਉਸ ਵਿਚ ਕੋਈ ਫਰਕ ਨਹੀਂ ਪਵੇਗਾ ਅਤੇ ਇਹ ਜਜ਼ਬਾਤੀ ਪਰੇਸ਼ਾਨੀ, ਅਤੇ/ਜਾਂ ਸਰੀਰਕ ਬੇਆਰਾਮੀ ਪੈਦਾ ਕਰ ਸਕਦਾ ਹੈ। ਜਦੋਂ ਸਰੀਰ ਖਾਣ ਜਾਂ ਪੀਣ ਦੀ ਇੱਛਾ ਨਾ ਰੱਖਦਾ ਹੋਵੇ ਤਾਂ ਉਸ ਵਿਅਕਤੀ ਨੂੰ ਆਈ ਵੀ ਲਾਉਣਾ ਜ਼ਰੂਰੀ ਨਹੀਂ ਹੈ ਅਤੇ ਅਜਿਹਾ ਕਰਨਾ ਅਕਸਰ ਸਰੀਰ ਵਿਚ ਪਾਣੀ ਦੇ ਜ਼ਿਆਦਾ ਹੋਣ ਅਤੇ ਫੇਫੜਿਆਂ ਦੇ ਜੰਮਣ ਦਾ ਕਾਰਨ ਬਣ ਸਕਦਾ ਹੈ। ਜੇ ਮੂੰਹ ਨੂੰ ਗਿੱਲਾ ਰੱਖਿਆ ਜਾਵੇ ਤਾਂ ਸਰੀਰ ਵਿਚ ਪਾਣੀ ਦੀ ਘਾਟ ਬੇਆਰਾਮੀ ਵਾਲੀ ਨਹੀਂ ਹੈ।

ਇਸੇ ਤਰ੍ਹਾਂ, ਨੱਕ ਵਿਚ ਟਿਊਬ ਲਗਾ ਕੇ ਜਾਂ ਪੇਟ ਵਿਚ ਪਾ ਕੇ ਖਾਣਾ ਦੇਣਾ ਮਰਨ ਦੇ ਕਾਰਜ ਨੂੰ ਨਹੀਂ ਬਦਲਦਾ। ਟਿਊਬ ਨਾਲ ਖਾਣਾ ਦੇਣ ਦੇ ਸਾਈਡ ਇਫੈਕਟ ਹਨ ਜਿਨ੍ਹਾਂ ਵਿਚ ਫੇਫੜਿਆਂ ਵਿਚ ਖਾਣਾ ਜਾਣ ਨਾਲ ਫੇਫੜੇ ਦੀ ਇਨਫੈਕਸ਼ਨ ਹੋਣਾ ਅਤੇ ਖਾਣੇ ਨਾਲ ਬੇਆਰਾਮੀ ਹੋਣਾ ਵੀ ਸ਼ਾਮਲ ਹਨ। ਆਪਣੇ ਪਿਆਰੇ ਦੇ ਖਾਣ ਅਤੇ ਪੀਣ ਬਾਰੇ ਜੇ ਤੁਹਾਡੇ ਮਨ ਵਿਚ ਕੋਈ ਫਿਕਰ ਹੋਵੇ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਉਸ ਦੀ ਸੰਭਾਲ ਕਰ ਰਹੀ ਟੀਮ ਨਾਲ ਗੱਲ ਕਰੋ।

Return to Page 1

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਬਰਫ ਦੇ ਛੋਟੇ ਟੁਕੜੇ, ਜਮਾਏ ਹੋਏ ਜੂਸ/ਕੁਲਫੀਆਂ ਮੂੰਹ ਨੂੰ ਤਾਜ਼ਾ ਕਰ ਸਕਦੇ ਹਨ। ਨਿਗਲਣ ਦੀ ਸਮਰੱਥਾ ਵਿਚ ਕਮੀ ਤੋਂ ਜਾਣੂ ਰਹੋ। ਨਿਗਲਣ ਲਈ ਲੋੜੀਂਦੇ ਰੈਫਲੈਕਸਿਜ਼ ਮੱਠੇ ਪੈ ਗਏ ਹੋ ਸਕਦੇ ਹਨ, ਇਸ ਕਰਕੇ ਉਸ ਨੂੰ ਪੀਣ ਲਈ ਨਾ ਦਿਉ ਜੇ ਉਹ ਨਿਗਲਣ ਤੋਂ ਛੇਤੀ ਬਾਅਦ ਖੰਘਦਾ/ਖੰਘਦੀ ਹੈ। ਉਸ ਦਾ ਸਰੀਰ ਉਸ ਨੂੰ ਦੱਸਦਾ ਹੈ ਜਦੋਂ ਉਸ ਨੂੰ ਖਾਣ ਦੀ ਇੱਛਾ ਨਹੀਂ ਹੁੰਦੀ ਜਾਂ ਉਹ ਖਾਣਾ ਜਾਂ ਪੀਣਾ ਝੱਲ ਨਹੀਂ ਸਕਦਾ/ਸਕਦੀ। ਇਸ ਇੱਛਾ ਦਾ ਮਰਨਾ ਇਹ ਨਿਸ਼ਾਨੀ ਹੈ ਕਿ ਵਿਅਕਤੀ ਮੌਤ ਲਈ ਤਿਆਰ ਹੋ ਰਿਹਾ ਹੈ। ਜੇ ਤੁਹਾਡਾ ਪਿਆਰਾ ਹੁਣ ਨਿਗਲ ਨਹੀਂ ਸਕਦਾ ਤਾਂ ਮੂੰਹ ਅਤੇ ਬੁੱਲ੍ਹਾਂ ਨੂੰ ਗਿੱਲੇ ਅਤੇ ਨਮ ਰੱਖਣ ਲਈ ਤਰ ਫੈਹੇ ਜਾਂ ਪਾਣੀ ਵਿਚ ਘੁਲਨਸ਼ੀਲ ਲੁਬਰੀਕੈਂਟ ਵਰਤੋ।

ਮਿਲਣਸਾਰਤਾ ਘਟਣਾ

ਕੁਝ ਲੋਕ ਹਰ ਵੇਲੇ ਆਪਣੇ ਕੋਲ ਹੋਰ ਲੋਕਾਂ ਦਾ ਹੋਣਾ ਪਸੰਦ ਕਰਦੇ ਹਨ। ਕੁਝ ਹੋਰ ਇਕੱਲਾ ਰਹਿਣਾ ਚਾਹੁੰਦੇ ਹੋ ਸਕਦੇ ਹਨ ਜਾਂ ਇਕ ਜਾਂ ਬਹੁਤ ਘੱਟ ਲੋਕਾਂ ਨਾਲ ਹੋਣਾ ਚਾਹੁੰਦੇ ਹਨ। ਅਜਿਹਾ ਹੋਣਾ ਕੁਦਰਤੀ ਹੈ ਕਿਉਂਕਿ ਉਹ ਕਮਜ਼ੋਰ ਅਤੇ ਥੱਕਿਆ ਹੋਇਆ ਹੋਵੇਗਾ/ਹੋਵੇਗੀ ਅਤੇ ਬਹੁਤੀ ਗੱਲਬਾਤ ਕਰਨ ਦੇ ਯੋਗ ਨਹੀਂ ਹੋਵੇਗਾ/ਹੋਵੇਗੀ। ਤੁਹਾਨੂੰ ਇਹ ਮਹਿਸੂਸ ਹੋ ਸਕਦਾ ਹੈ ਕਿ ਬੀਮਾਰ ਇਕੱਲਾ ਹੈ ਅਤੇ ਉਸ ਨੂੰ ਜ਼ਿੰਦਗੀ ਵਿਚ ਜ਼ਿਆਦਾ ਹਿੱਸਾ ਲੈਣ ਦੀ ਲੋੜ ਹੈ। ਪਰ, ਇਹ ਨਾ ਮਹਿਸੂਸ ਕਰੋ ਕਿ ਤੁਹਾਡੇ ਲਈ ਹਰ ਵੇਲੇ ਗੱਲ ਕਰਨਾ ਜ਼ਰੂਰੀ ਹੈ, ਕਦੇ ਕਦੇ ਰਲ ਕੇ ਚੁੱਪ ਚਾਪ ਬਹਿਣਾ ਹੀ ਚੰਗਾ ਹੁੰਦਾ ਹੈ।

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਉਸ ਵਿਅਕਤੀ ਨੂੰ ਯਕੀਨ ਦਿਵਾਉ ਕਿ ਜੇ ਉਹ ਗੱਲ ਨਹੀਂ ਕਰਨਾ ਚਾਹੁੰਦੇ, ਜਾਂ ਜੇ ਤੁਹਾਡੇ ਸ਼ਬਦਾਂ ਦਾ ਹੁੰਗਾਰਾ ਨਹੀਂ ਭਰ ਸਕਦੇ ਤਾਂ ਆਰਾਮ ਕਰਨਾ ਠੀਕ ਹੈ।

Return to Page 1

ਨੀਂਦ

ਉਹ ਵਿਅਕਤੀ ਜ਼ਿਆਦਾ ਸਮਾਂ ਸੌਂ ਕੇ ਗੁਜ਼ਾਰ ਸਕਦਾ ਹੈ ਅਤੇ ਗੱਲਬਾਤ ਨਾ ਸੁਣਦਾ, ਹੁੰਗਾਰਾ ਨਾ ਭਰਦਾ ਲੱਗ ਸਕਦਾ ਹੈ ਅਤੇ ਕਦੇ ਕਦੇ ਜਗਾਉਣਾ ਔਖਾ ਹੋ ਸਕਦਾ ਹੈ। ਇਹ ਕੁਦਰਤੀ ਤਬਦੀਲੀ, ਸਰੀਰ ਅਤੇ ਦਿਮਾਗ ਦੇ ਮੈਟਾਬਲਿਜ਼ਮ ਵਿਚ ਤਬਦੀਲੀਆਂ ਕਾਰਨ ਵੀ ਹੁੰਦੀ ਹੈ। ਉਸ ਨਾਲ ਬੈਠੋ ਅਤੇ ਉਸ ਦਾ ਹੱਥ ਫੜੋ, ਹੌਲੀ ਹੌਲੀ ਅਤੇ ਕੁਦਰਤੀ ਲਹਿਜੇ ਨਾਲ ਬੋਲੋ। ਤੁਸੀਂ ਉਸ ਨਾਲ ਉਦੋਂ ਸਮਾਂ ਗੁਜ਼ਾਰਨਾ ਚਾਹੁੰਦੇ ਹੋ ਸਕਦੇ ਹੋ ਜਦੋਂ ਉਹ ਜ਼ਿਆਦਾ ਸੁਚੇਤ ਹੁੰਦਾ/ਹੁੰਦੀ ਹੈ ਪਰ ਜਦੋਂ ਵੀ ਤੁਸੀਂ ਕੋਲ ਹੋ ਸਕਦੇ ਹੋਵੋ, ਉਦੋਂ ਹੋਣਾ ਵੀ ਠੀਕ ਹੈ।

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਉਸ ਨਾਲ ਸਿੱਧੀ ਆਮ ਆਮ ਵਾਂਗ ਬੋਲੋ, ਭਾਵੇਂ ਕਿ ਕੋਈ ਜਵਾਬ ਨਾ ਵੀ ਮਿਲੇ। ਕਦੇ ਵੀ ਇਹ ਨਾ ਮੰਨ ਲਵੋ ਕਿ ਉਹ ਵਿਅਕਤੀ ਸੁਣ ਜਾਂ ਮਹਿਸੂਸ ਨਹੀਂ ਕਰ ਸਕਦਾ, ਕਿਉਂਕਿ ਅਸੀਂ ਇਹ ਨਹੀਂ ਜਾਣਦੇ ਕਿ ਜ਼ਿੰਦਗੀ ਦੇ ਇਸ ਪੜਾ 'ਤੇ ਇੰਦਰੀਆਂ ਕਿੰਨਾ ਕੁ ਚੰਗੀ ਤਰ੍ਹਾਂ ਕੰਮ ਕਰਦੀਆਂ ਹੁੰਦੀਆਂ ਹਨ।

ਬੇਆਰਾਮੀ

ਬੀਮਾਰ ਵਿਅਕਤੀ ਬੇਆਰਾਮੀ ਵਾਲੀ ਅਤੇ ਦੁਹਰਾਉ ਵਾਲੀ ਹਿਲਜੁਲ ਕਰ ਸਕਦਾ ਹੈ ਜਿਵੇਂ ਕਿ ਬੈੱਡ ਦੀਆਂ ਚਾਦਰਾਂ ਜਾਂ ਕੱਪੜਿਆਂ ਨੂੰ ਖਿੱਚਣਾ। ਅਜਿਹਾ ਅਕਸਰ ਦਿਮਾਗ ਨੂੰ ਖੂਨ ਦੇ ਦੌਰੇ ਵਿਚ ਆਈ ਕਮੀ ਅਤੇ ਮੈਟਾਬੌਲਿਕ ਤਬਦੀਲੀਆਂ ਕਾਰਨ ਹੁੰਦਾ ਹੈ। ਘਬਰਾਉ ਨਾ, ਅਤੇ ਦਖਲ ਨਾ ਦਿਉ ਜਾਂ ਅਜਿਹੀ ਹਿਲਜੁਲ ਨੂੰ ਰੋਕਣ ਦੀ ਕੋਸ਼ਿਸ਼ ਨਾ ਕਰੋ। ਜੇ ਤੁਹਾਨੂੰ ਲੱਗਦਾ ਹੈ ਕਿ ਤੁਹਾਡਾ ਪਿਆਰਾ ਕਿਸੇ ਕਾਰਨ ਕਰਕੇ ਬੇਆਰਾਮ ਹੈ, ਜਿਵੇਂ ਕਿ ਦਰਦ, ਸਾਹ ਦੀ ਕਮੀ ਜਾਂ ਬੇਆਰਾਮੀ ਵਾਲੀ ਅਵਸਥਾ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਆਪਣੇ ਪਿਆਰੇ ਦੀ ਸੰਭਾਲ ਕਰ ਰਹੀ ਟੀਮ ਨੂੰ ਦੱਸੋ ਤਾਂ ਜੋ ਉਹ ਮਦਦ ਕਰ ਸਕਣ।

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਸ਼ਾਂਤ ਕਰਨ ਵਾਲਾ ਅਸਰ ਪਾਉਣ ਲਈ, ਹੌਲੀ ਅਤੇ ਕੁਦਰਤੀ ਤਰੀਕੇ ਨਾਲ ਬੋਲੋ, ਹੌਲੀ ਹੌਲੀ ਹੱਥ ਜਾਂ ਮੱਥੇ 'ਤੇ ਮਾਲਸ਼ ਕਰੋ, ਉਸ ਨੂੰ ਪੜ੍ਹ ਕੇ ਸੁਣਾਉ ਜਾਂ ਧੀਮਾ ਧੀਮਾ ਸੰਗੀਤ ਲਾਉ।

Return to Page 1

ਪਰੇਸ਼ਾਨੀ

ਵਿਅਕਤੀ ਸਮੇਂ, ਸਥਾਨ ਅਤੇ ਆਪਣੇ ਆਲੇ ਦੁਆਲੇ ਦੇ ਲੋਕਾਂ ਦੀ ਪਛਾਣ ਬਾਰੇ ਭੰਬਲਭੂਸੇ ਵਿਚ ਹੋ ਸਕਦਾ ਹੈ, ਜਿਸ ਵਿਚ ਨੇੜੇ ਦੇ ਜਾਣੇ-ਪਛਾਣੇ ਲੋਕ ਵੀ ਸ਼ਾਮਲ ਹਨ। ਤੁਹਾਡੇ ਪਿਆਰੇ ਦੀ ਸੰਭਾਲ ਕਰ ਰਹੀ ਟੀਮ ਭੰਬਲਭੂਸੇ ਦੇ ਉਨ੍ਹਾਂ ਕਾਰਨਾਂ ਦੀ ਪਛਾਣ ਕਰਨ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰੇਗੀ ਜਿਹੜੇ ਠੀਕ ਕੀਤੇ ਜਾ ਸਕਦੇ ਹੋਣ ਪਰ ਅਕਸਰ ਅਜਿਹਾ ਮੌਤ ਦੇ ਕਾਰਜ ਦੇ ਕੁਦਰਤੀ ਹਿੱਸੇ ਵਜੋਂ ਵਾਪਰ ਸਕਦਾ ਹੈ।

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਬੋਲਣ ਤੋਂ ਪਹਿਲਾਂ ਆਪਣਾ ਨਾਂ ਲੈ ਕੇ ਬੋਲੋ। ਆਪਣੇ ਪਿਆਰੇ ਦੇ ਆਰਾਮ ਲਈ ਕੋਈ ਜ਼ਰੂਰੀ ਚੀਜ਼ ਕਰਨ ਵੇਲੇ ਹੌਲੀ ਹੌਲੀ, ਸਾਫ ਸਾਫ ਅਤੇ ਸੌਖੇ ਸਬ਼ਦਾਂ ਵਿਚ ਬੋਲੋ, ਜਿਵੇਂ ਕਿ, "ਇਹ ਸਮਾਂ ਆਪਣੀ ਦਵਾਈ ਲੈਣ ਦਾ ਹੈ ਤਾਂ ਜੋ ਤੁਹਾਡੇ ਦਰਦ ਨਾ ਹੋਵੇ"। ਇਹ ਨਾ ਮਹਿਸੂਸ ਕਰੋ ਕਿ ਤੁਹਾਨੂੰ ਉਸ ਦੀ ਪਰੇਸ਼ਾਨੀ ਦੂਰ ਕਰਨੀ ਪਵੇਗੀ ਕਿਉਂਕਿ ਇਸ ਨਾਲ ਤੁਹਾਡੇ ਪਿਆਰੇ ਦੀ ਪੀੜਾ ਵਧ ਸਕਦੀ ਹੈ।

ਪਿਸ਼ਾਬ ਦਾ ਘਟਣਾ

ਆਮ ਤੌਰ 'ਤੇ ਵਿਅਕਤੀ ਨੂੰ ਪਿਸ਼ਾਬ ਆਉਣਾ ਘਟ ਜਾਂਦਾ ਹੈ ਅਤੇ ਇਹ ਚਾਹ-ਰੰਗਾ ਅਤੇ ਸੰਘਣਾ ਹੋ ਸਕਦਾ ਹੈ। ਅਜਿਹਾ ਪੀਣ ਵਾਲੀਆਂ ਚੀਜ਼ਾਂ ਦੀ ਘਾਟ ਦੇ ਨਾਲ ਨਾਲ ਗੁਰਦਿਆਂ ਵਿਚ ਦੌਰੇ ਦੀ ਘਾਟ ਕਾਰਨ ਹੁੰਦਾ ਹੈ। ਨਰਸ ਇਹ ਫੈਸਲਾ ਕਰ ਸਕਦੀ ਹੈ ਕਿ ਕੀ ਪਿਸ਼ਾਬ ਲਈ ਨਾਲੀ ਲਾਉਣ ਦੀ ਲੋੜ ਹੈ ਜਾਂ ਨਹੀਂ।

Return to Page 1

ਸਾਹ–ਕ੍ਰਿਆ ਵਿਚ ਤਬਦੀਲੀਆਂ

ਮੌਤ ਦੇ ਨੇੜੇ ਵਿਅਕਤੀ ਦੇ ਸਾਹ ਦੀ ਆਮ ਕ੍ਰਿਆ ਬਦਲ ਸਕਦੀ ਹੈ। ਇਕ ਖਾਸ ਕ੍ਰਿਆ, ਬੇਨੇਮੇ ਓਪਰੇ ਓਪਰੇ ਸਾਹ ਆਉਣਾ, ਜਾਂ 5 ਤੋਂ 30 ਸਕਿੰਟਾਂ ਤੱਕ ਸਾਹ ਨਾ ਆਉਣਾ ਅਤੇ ਬਾਅਦ ਵਿਚ ਡੂੰਘਾ ਸਾਹ ਆਉਣਾ ਹੈ। ਕਦੇ ਕਦੇ ਸਾਹ ਬਾਹਰ ਕੱਢਣ 'ਤੇ ਹੂੰਗਰ ਵੱਜਣ ਦੀ ਆਵਾਜ਼ ਆਉਂਦੀ ਹੈ। ਇਹ ਪੀੜਾ ਨਹੀਂ ਹੈ ਸਗੋਂ ਆਰਾਮਦੇਹ ਹੋਈਆਂ ਆਵਾਜ਼ੀ–ਤੰਦਾਂ ਉੱਪਰ ਦੀ ਹਵਾ ਲੰਘਣ ਦੀ ਆਵਾਜ਼ ਹੈ। ਇਹ ਕ੍ਰਿਆਵਾਂ ਬਹੁਤ ਆਮ ਹਨ ਅਤੇ ਦਿਮਾਗ ਦੇ ਉਸ ਹਿੱਸੇ ਵਿਚ ਖੂਨ ਦੇ ਦੌਰੇ ਦੇ ਘਟਣ ਦੀ ਨਿਸ਼ਾਨੀ ਹਨ ਜਿਹੜਾ ਸਾਹ ਨੂੰ ਕੰਟਰੋਲ ਕਰਦਾ ਹੈ।

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਸਿਰ ਨੂੰ ਉੱਚਾ ਚੁੱਕਣ ਅਤੇ/ਇਕ ਪਾਸੇ ਨੂੰ ਕਰਨ ਨਾਲ ਸਾਹ–ਕ੍ਰਿਆ ਬਦਲ ਸਕਦੀ ਹੈ ਪਰ ਅਜਿਹਾ ਕਰਨਾ ਜ਼ਰੂਰੀ ਨਹੀਂ ਹੈ ਕਿਉਂਕਿ ਇਹ ਮੌਤ ਹੋਣ ਦਾ ਇਕ ਆਮ ਹਿੱਸਾ ਹੈ। ਆਪਣੇ ਪਿਆਰੇ ਦਾ ਹੱਥ ਫੜੋ। ਹੌਲੀ ਹੌਲੀ ਅਤੇ ਧਰਵਾਸ ਦਿੰਦੇ ਹੋਏ ਬੋਲੋ।

Return to Page 1

ਘੋਰੜੂ ਵੱਜਣਾ

ਵਿਅਕਤੀ ਦੀ ਛਾਤੀ ਵਿੱਚੋਂ ਗੁੜ ਗੁੜ ਦੀਆਂ ਆਵਾਜ਼ਾਂ ਆ ਸਕਦੀਆਂ ਹਨ ਜੋ ਕਿ ਕਾਫੀ ਬਣਾਉਣ ਵਾਲੀ ਮਸ਼ੀਨ ਦੀ ਆਵਾਜ਼ ਵਰਗੀਆਂ ਸੁਣਾਈ ਦੇ ਸਕਦੀਆਂ ਹਨ। ਇਹ ਆਵਾਜ਼ਾਂ ਬਲਗਮ ਦੀਆਂ ਹੁੰਦੀਆਂ ਹਨ ਜਿਹੜੀ ਤੁਹਾਡੇ ਪਿਆਰੇ ਦੇ ਚੁਕੰਨੇ ਅਤੇ ਜਾਗਦੇ ਹੋਣ ਵੇਲੇ ਨਿਕਲ ਜਾਣੀ ਸੀ। ਕਦੇ ਕਦੇ ਇਹ ਆਵਾਜ਼ਾਂ ਬਹੁਤ ਹੀ ਉੱਚੀਆਂ ਹੋ ਜਾਂਦੀਆਂ ਹਨ ਅਤੇ ਇਨ੍ਹਾਂ ਨੂੰ ਸੁਣਨਾ ਦੁਖਦਾਈ ਹੋ ਸਕਦਾ ਹੈ। ਆਪਣੇ ਪਿਆਰੇ 'ਤੇ ਨੇੜਿਉਂ ਨਜ਼ਰ ਰੱਖੋ ਅਤੇ ਇਹ ਗੱਲ ਨੋਟ ਕਰੋ ਕਿ ਆਮ ਤੌਰ 'ਤੇ ਉਹ ਆਪਣੇ ਸਰੀਰ ਦੇ ਕਾਰਜਾਂ ਤੋਂ ਬੇਖਬਰ ਹੁੰਦੇ ਹਨ। ਇਸ ਨੂੰ ਦੇਖਣਾ ਅਕਸਰ ਤੁਹਾਡੇ ਲਈ ਔਖਾ ਹੁੰਦਾ ਹੈ ਨਾ ਕਿ ਮਰੀਜ਼ ਲਈ। ਬਲਗਮ ਬਾਹਰ ਕੱਢਣ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰਨਾ ਬੇਆਰਾਮੀ ਵਾਲਾ ਹੁੰਦਾ ਹੈ ਅਤੇ ਬਹੁਤੀ ਵਾਰੀ ਕਾਮਯਾਬੀ ਨਹੀਂ ਮਿਲਦੀ। ਰੇਸ਼ਾ ਘਟਾਉਣ ਵਾਲੀਆਂ ਦਵਾਈਆਂ ਦਿੱਤੀਆਂ ਜਾ ਸਕਦੀਆਂ ਹਨ।

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਬੈੱਡ ਦਾ ਸਿਰ ਵਾਲਾ ਪਾਸਾ ਉੱਚਾ ਕਰ ਦਿਉ ਤਾਂ ਜੋ ਰੇਸ਼ਾ ਹੇਠਾਂ ਰਹੇ ਅਤੇ ਉੱਪਰ ਗਲ਼ੇ ਨੂੰ ਉਤੇਜਤ ਨਾ ਕਰੇ। ਸਿਰ ਨੂੰ ਉੱਚਾ ਕਰਨ ਅਤੇ/ਜਾਂ ਇਕ ਪਾਸੇ ਨੂੰ ਕਰਨ ਨਾਲ ਗੁੜ ਗੁੜ ਦੀਆਂ ਆਵਾਜ਼ਾਂ ਘਟ ਸਕਦੀਆਂ ਹਨ। ਆਪਣੇ ਪਿਆਰੇ ਦਾ ਹੱਥ ਫੜੋ। ਹੌਲੀ ਹੌਲੀ ਅਤੇ ਧਰਵਾਸ ਦਿੰਦੇ ਹੋਏ ਬੋਲੋ।

ਰੰਗ ਵਿਚ ਤਬਦੀਲੀਆਂ

ਵਿਅਕਤੀ ਦੀਆਂ ਬਾਂਹਾਂ ਅਤੇ ਲੱਤਾਂ ਠੰਢੀਆਂ, ਗਰਮ ਜਾਂ ਬਦਰੰਗ ਹੋ ਸਕਦੀਆਂ ਹਨ। ਖੂਨ ਦੇ ਦੌਰੇ ਦੇ ਘਟਣ ਨਾਲ ਸਰੀਰ ਦਾ ਹੇਠਲਾ ਹਿੱਸਾ ਬਦਰੰਗ ਹੋ ਸਕਦਾ ਹੈ। ਇਹ ਇਕ ਕੁਦਰਤੀ ਤਬਦੀਲੀ ਹੈ ਜੋ ਇਹ ਇਸ਼ਾਰਾ ਕਰਦੀ ਹੈ ਕਿ ਖੂਨ ਦਾ ਦੌਰਾ ਬਹੁਤ ਹੀ ਜੀਵਨਮਈ ਅੰਗਾਂ ਦੀ ਮਦਦ ਲਈ ਸਾਂਭਿਆ ਜਾ ਰਿਹਾ ਹੈ। ਦਿਮਾਗ ਵਲੋਂ ਅਸਪਸ਼ਟ ਸੁਨੇਹੇ ਭੇਜੇ ਜਾਣ ਦੇ ਨਤੀਜੇ ਵਜੋਂ ਸਰੀਰ ਦਾ ਤਾਪਮਾਨ ਬੇਨੇਮਾ ਹੋ ਸਕਦਾ ਹੈ।

ਤੁਸੀਂ ਕੀ ਕਰ ਸਕਦੇ ਹੋ:

ਜੇ ਤੁਹਾਡਾ ਪਿਆਰਾ ਠੰਢਾ ਲੱਗੇ ਤਾਂ ਉਸ ਨੂੰ ਨਿੱਘਾ ਰੱਖੋ, ਪਰ ਬਿਜਲਈ ਕੰਬਲ ਦੀ ਵਰਤੋਂ ਨਾ ਕਰੋ। ਜੇ ਵਿਅਕਤੀ ਉੱਪਰ ਦਿੱਤਾ ਕੱਪੜਾ ਲਾਹੀ ਜਾਂਦਾ ਹੈ ਤਾਂ ਸਿਰਫ ਹਲਕੀ ਚਾਦਰ ਹੀ ਉੱਪਰ ਦਿਉ ਜਾਂ ਉਸ ਨੂੰ ਠੰਢਾ ਕਰਨ ਲਈ ਪੱਖਾ ਲਾਉ।

Return to Page 1

ਮੌਤ ਦੇ ਸਮੇਂ

- ਸਾਹ ਬੰਦ ਹੋ ਜਾਂਦਾ ਹੈ
- ਦਿਲ ਦੀ ਧੜਕਣ ਰੁਕ ਜਾਂਦੀ ਹੈ
- ਵਿਅਕਤੀ ਨੂੰ ਜਗਾਇਆ ਨਹੀਂ ਜਾ ਸਕਦਾ
- ਅੱਖਾਂ ਦੇ ਛੱਪਰ ਅੱਧੇ ਖੁੱਲ੍ਹੇ ਹੋ ਸਕਦੇ ਹਨ ਅਤੇ ਅੱਖਾਂ ਦੀ ਟਿਕਟਿਕੀ ਲੱਗੀ ਹੋ ਸਕਦੀ ਹੈ
- ਜਬਾੜ੍ਹੇ ਦੇ ਆਰਾਮ ਵਿਚ ਚਲੇ ਜਾਣ ਕਾਰਨ ਮੂੰਹ ਖੁੱਲ੍ਹਾ ਹੋ ਸਕਦਾ ਹੈ

ਤੁਹਾਡੇ ਪਿਆਰੇ ਦਾ ਮ੍ਰਿਤਕ ਸਰੀਰ ਕੁਝ ਸਮੇਂ ਲਈ ਅਜੇ ਨਰਮ ਅਤੇ ਗਰਮ ਹੁੰਦਾ ਹੈ। ਤੁਸੀਂ ਉਸ ਦੇ ਸਰੀਰ ਨੂੰ ਛੂਹ ਸਕਦੇ ਹੋ ਅਤੇ ਫੜ ਸਕਦੇ ਹੋ, ਜੇ ਤੁਸੀਂ ਅਜਿਹਾ ਕਰਨਾ ਚਾਹੁੰਦੇ ਹੋ। ਮੌਤ ਤੋਂ ਬਾਅਦ ਕੁਝ ਲੋਕ ਕੁਝ ਸਮੇਂ ਲਈ ਮ੍ਰਿਤਕ ਸਰੀਰ ਕੋਲ ਰਹਿਣਾ ਚਾਹੁੰਦੇ ਹਨ ਅਤੇ ਕੁਝ ਨਹੀਂ। ਆਪਣੇ ਪਿਆਰੇ ਦੇ ਮ੍ਰਿਤਕ ਸਰੀਰ ਕੋਲ ਓਨਾ ਸਮਾਂ ਗੁਜ਼ਾਰੋ ਜਿੰਨੇ ਸਮੇਂ ਦੀ ਤੁਹਾਨੂੰ ਲੋੜ ਹੈ।

ਕੁਝ ਲੋਕਾਂ ਦੀਆਂ ਅਧਿਆਤਮਿਕ ਜਾਂ ਸਭਿਆਚਾਰਕ ਰਵਾਇਤਾਂ ਹੁੰਦੀਆਂ ਹਨ ਜਿਹੜੀਆਂ ਮੌਤ ਤੋਂ ਬਾਅਦ ਕੀਤੀਆਂ ਜਾਂਦੀਆਂ ਹਨ। ਜੇ ਤੁਹਾਡੇ ਪਿਆਰੇ ਦੀ ਮੌਤ ਹਸਪਤਾਲ ਜਾਂ ਸੰਭਾਲ ਵਾਲੇ ਸਥਾਨ 'ਤੇ ਹੁੰਦੀ ਹੈ ਤਾਂ ਸਟਾਫ ਨੂੰ ਪਹਿਲਾਂ ਹੀ ਦੱਸੋ ਤਾਂ ਜੋ ਅਸੀਂ ਤੁਹਾਡੀ ਜ਼ਿਆਦਾ ਮਦਦ ਕਰ ਸਕੀਏ।

ਆਪਣੇ ਪਿਆਰੇ ਦੀ ਮੌਤ ਤੋਂ ਬਾਅਦ ਪਹਿਲੇ ਦਿਨ ਵਿਚ ਹੀ ਤੁਹਾਨੂੰ ਫਿਊਨਰਲ ਡਾਇਰੈਕਟਰ ਨਾਲ ਗੱਲ ਕਰਨ ਦੀ ਲੋੜ ਹੁੰਦੀ ਹੈ, ਪਰ ਅਜਿਹਾ ਫੌਰਨ ਕੀਤਾ ਜਾਣਾ ਜ਼ਰੂਰੀ ਨਹੀਂ ਹੈ। ਮੌਤ ਤੋਂ ਪਹਿਲਾਂ ਹੀ ਫਿਊਨਰਲ ਹੋਮ ਨਾਲ ਪ੍ਰਬੰਧ ਕਰ ਲੈਣੇ ਸਦਾ ਚੰਗਾ ਹੁੰਦਾ ਹੈ ਤਾਂ ਜੋ ਤੁਹਾਨੂੰ ਪਤਾ ਹੋਵੇ ਕਿ ਤੁਸੀਂ ਕਿਸ ਨੂੰ ਫੋਨ ਕਰਨਾ ਹੈ, ਖਾਸ ਕਰਕੇ ਉਸ ਸਮੇਂ ਜਦੋਂ ਤੁਸੀਂ ਉਦਾਸ ਮਹਿਸੂਸ ਕਰ ਰਹੇ ਹੁੰਦੇ ਹੋ।

Return to Page 1

ਇਹ ਜਾਣਕਾਰੀ ਇਸ ਕਰਕੇ ਦਿੱਤੀ ਗਈ ਹੈ ਤਾਂ ਜੋ ਜ਼ਿੰਦਗੀ ਤੋਂ ਮੌਤ ਵਿਚ ਤਬਦੀਲੀ ਵੱਧ ਤੋਂ ਵੱਧ ਕੁਦਰਤੀ ਰੂਪ ਵਿਚ ਹੋ ਸਕੇ।

ਜੇ ਤੁਹਾਡੇ ਮਨ ਵਿਚ ਕੋਈ ਸਵਾਲ ਹੋਵੇ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸੰਭਾਲ ਕਰਨ ਵਾਲੀ ਆਪਣੀ ਟੀਮ ਤੋਂ ਪੁੱਛੋ।

ਵੈਨਕੂਵਰ ਕੋਸਟਲ ਹੈਲਥ ਅਤੇ ਪ੍ਰੋਵੀਡੈਂਸ ਹੈਲਥ ਕੇਅਰ ਵਿਖੇ ਵਰਤੋਂ ਲਈ, ਨੇਬਰਹੁੱਡ ਵਿਜ਼ਟਿੰਗ ਨਰਸਿਜ਼ ਐਸੋਸੀਏਸ਼ਨ ਆਫ ਵੈੱਸਟ ਚੈਸਟਰ, ਪੈਨਸਲਵੇਨੀਆ, ਅਮਰੀਕਾ ਤੋਂ ਆਗਿਆ ਲੈ ਕੇ ਅਪਣਾਇਆ।

ਹੋਰ ਕਾਪੀਆਂ ਲੈਣ ਲਈ, **http://vch.eduhealth.ca** 'ਤੇ ਵੈੱਬਸਾਈਟ ਦੇਖੋ ਜਾਂ **phem@vch.ca** 'ਤੇ ਈਮੇਲ ਕਰੋ ਅਤੇ ਕੈਟਾਲੌਗ ਨੰਬਰ **GV.100.P919.PU** ਦੱਸੋ।

Actively Dying: The End of Life (EOL) Care check list

Points to consider when patients enter the dying phase:

- Review a patient's goals of care, preferred place of care, what to do in an emergency.
- Refer to home nursing if not already arranged.
- Ensure that the required forms are completed (No CPR and/or Planned Home Death).
- Discontinue non-essential medications.
- Arrange for subcutaneous (SC) / transdermal medication administration or a drug kit to be placed in the home when a patient is no longer able to take medications by mouth (refer Appendix F).
- Arrange for a hospital bed +/- pressure relief mattress.
- Arrange for a Foley catheter as needed.
- Leave an order for a SC anti-secretion medication (e.g., atropine, glycopyrrolate).

Source: Guidelines and Protocols Advisory Committee (GPAC): Palliative Care for the Patient with Incurable Cancer or Advanced Disease - Part 1: Approach to Care: June 15, 2010

Being with a person who is dying is an emotional time. This information may help you to prepare for a death that is expected. If you understand the normal changes to expect and how to help, it may make this time easier.

Changes to expect when death is near and *ways you can help*

The body begins to shut down its systems as it prepares itself to stop working. These changes are normal and natural. The best way to help during this stage is to give support and comfort. Each person is different so not all these signs and symptoms will occur, and they may not occur in the same order.

Sleeping

The person may speak less, spend more and more time sleeping and be difficult to wake up. This is normal as the body's energy level goes down.

Tell the person that it is okay to sleep. Sit and hold their hand. Speak softly and naturally. Plan to spend time together when they are most awake and aware. At this point, it is more important to 'be with' them than 'do for' them. Don't assume that the person cannot hear; hearing is said to be the last sense to be lost.

Confusion

The person may become confused about time and place. They may not recognize people around them including close friends and relatives.

Speak calmly and clearly. Tell the person who you are, the time and who is in the room.

Restlessness

The person may be restless and repeat movements such as pulling at the bed linens or picking at unseen objects in the air. They may see people who are not there. This happens partly because of the reduced flow of blood to the brain and other changes in the body. Medications for comfort may be recommended to help settle restlessness if required.

Do not be afraid. Speak quietly and naturally. Try to reassure them. Do not try to hold the person down or stop their movements unless it is necessary. A gentle massage or some relaxing music may also help.

Less desire to be with others

Some people like to have others with them all the time. Some want to be alone or with just one person.

Don't feel that you must talk or always be there. Sometimes it is good just to sit quietly together or let the person be alone.

Continued inside…

If you have any questions or would like more information about Hospice services please contact the Vancouver Home Hospice Palliative Care Service Office or your local Community Health Centre/Office:

Vancouver Home Hospice Palliative Care Service
300-999 West Broadway
604-742-4010

Robert and Lily Lee Family Community Health Centre
1669 East Broadway
604-675-3980

South Community Health Office
6405 Knight Street
604-321-6151

Evergreen Community Health Centre
3425 Crowley Drive (at Joyce)
604-872-2511

Pacific Spirit Community Health Centre
2110 West 43rd Avenue
604-261-6366

Pender Community Health Centre
59 West Pender Street
604-669-9181

Three Bridges Community Health Centre
1292 Hornby Street
604-736-9844

Raven Song Community Health Centre
2450 Ontario Street
604-709-6400

Palliative Access Line
604-263-7255

For more copies, go online at **http://vch.eduhealth.ca** or email **phem@vch.ca** and quote Catalogue No. **GV.100.D43**

Next -->

Return to Page 1

When Death is Close at Hand

How to know & what to do

Vancouver Home Hospice
Palliative Care Service

Return to Page 1

Loss of appetite and swallowing

The person may want less to eat and drink as the body slows down. This is a normal way to respond to disease.

Let the person decide what and how much food or drink they want. If the person is still eating and drinking, offer small servings of favorite food or drink without "forcing". Small ice chips or frozen juices may be refreshing. Focus on enjoyment rather than amount.

The person may lose the ability to swallow. At this point, food or drink can pass into the lungs rather than the stomach. The person will not feel thirsty if you keep the mouth moist.

Wipe inside the person's mouth with a wet swab to satisfy thirst and help keep the mouth clean.

Incontinence

The urine may look darker (more tea coloured) as the person drinks less. They may need to move their bowels less often, although bowel movements still need to occur. The person may lose control of the bladder or bowels as the muscles in those areas begin to relax.

Keep the person clean and comfortable. The nurse can help with suggestions for padding or a catheter (ordered by the doctor) if this is needed.

Changes in breathing pattern

The person's regular breathing pattern may change. Breathing may be irregular or shallow or rapid. It may stop for 5 – 30 seconds and then start again. Sometimes there is a moaning-like sound when the person breathes out. This does not mean the person is in distress, but is just the sound of air passing over relaxed vocal cords. The person may make gurgling sounds as saliva pools in the back of the throat. This usually does not bother them and can be reduced with medication.

The person may be more comfortable if you raise the head of the bed or turn them on their side. Hold their hand. Speak gently and reassuringly.

Colour and temperature changes

Arms and legs begin to cool as the circulation slows down to these areas. This is a normal sign that the body is saving blood for the vital organs. The face may look paler and hands and feet may take on a purple-blue colour. The underside of the body may become darker. The person's temperature may go up and down because the brain is sending unclear messages.

Use just enough covering to keep the person comfortable.

Giving "permission" to die

The dying person may sometimes try to hold on, even though it makes them very uncomfortable. The person may need to hear that those left behind will be okay.
If the family can reassure and release the dying person from this concern, they are offering a great gift.

Saying goodbye

When death is close, it is time to say goodbye in personal ways. This allows the person to let go.

It may be helpful to just lay on the bed, hold a hand, and say what you need to say. Do not be concerned if tears appear. They are a natural part of making peace and saying goodbye. There is no need to apologize or hide them.

At the time of death:

- the person cannot be awakened
- breathing stops
- heartbeat and pulses stop
- the eyes will be fixed in one direction and may be open or closed
- the mouth may be open as the jaw relaxes
- the bowel and bladder may release their contents

What to do if you think death has occurred:

- **DO NOT** call 911, the police or the fire department. These calls are not necessary when death is expected.
- Call your family doctor to come and pronounce death.
- If you are not sure about what to do, call the Community Health Nurse (CHN) or the "on call" service.
- Call any family members, friends or spiritual advisor if you would like them to be there with you.
- Call the funeral home when you are ready. There is not a rush to call if you wish to take extra time with the person who has died. Once you call the funeral home, they usually come within one hour.
- Call the CHN if you have any concerns about the death or expected death.

This pamphlet has been adapted from the material provided by:
Neighborhood Visiting Nurses Association of West Chester, Pennsylvania

BRITISH COLUMBIA
Ministry of Health Services

Vital Info
Informational Updates for Vital Statistics Agency Service Providers

COMPLETING THE MEDICAL CERTIFICATE OF DEATH

This is an information bulletin for physicians. A Handbook is available on the BC Vital Statistics website http://www.vs.gov.bc.ca located in→ Service Information → Statistics, Reports and Legislation →Special Interest → Handbooks. A revision of this handbook will be available in 2011.

Vital Statistics Act (Excerpt)

Medical certificate

18 (1) A medical certificate must be prepared in accordance with subsection (2) in any of the following circumstances:

(a) if a medical practitioner

(i) attended the deceased during the deceased's last illness,

(ii) is able to certify the medical cause of death with reasonable accuracy, and

(iii) has no reason to believe that the deceased died under circumstances which require an investigation or inquest under the *Coroners Act*;

(b) if the death was natural and a medical practitioner

(i) is able to certify the medical cause of death with reasonable accuracy, and

(ii) has received the consent of a coroner to complete and sign the medical certificate;

(c) if a coroner conducts an investigation or inquest into the death under the Coroners Act.

(2) Within 48 hours after the death, the medical practitioner or the coroner, as applicable, must

(a) complete and sign a medical certificate in the form required by the chief executive officer stating in it the cause of death according to the international classification, and

(b) make the certificate available to the funeral director.

Return to Page 1

(3) If

(a) a death occurred without the attendance of a medical practitioner during the last illness of the deceased, or

(b) the medical practitioner who attended the deceased is for any reason unable to complete the medical certificate within 48 hours after the death, the funeral director or the medical practitioner, as the case may be, must promptly notify the coroner.

(4) If a cause of death cannot be determined within 48 hours after the death and

(a) an autopsy is performed, or

(b) an investigation or inquest is commenced under the Coroners Act,and the medical practitioner who performs the autopsy or the coroner who commences an investigation or inquest under the Coroners Act, as the case may be, considers that the body is no longer required for the purposes of the autopsy, investigation or inquest, the medical practitioner or the coroner, as the case may be, may, despite subsection (1), issue and must make available to the funeral director an interim medical certificate in the form required by the chief executive officer.

(5) After the conclusion of the autopsy, investigation or inquest referred to in subsection (4),

(a) the medical practitioner who performed the autopsy, or the coroner, must complete and sign the medical certificate referred to in subsection (2) and deliver it to the chief executive officer, and

(b) the coroner must deliver a copy of any report prepared under section 20 (4) (b) or 25 (2) of the *Coroners Act* to the chief executive officer.

Certifying Physician's Responsibility:

If the *immediate cause of death* entered on line (a) was due to an accident, poisoning, or violence, ***Medical Certification must be completed by a coroner.***

The attending Physician at the time of death is responsible for completion of the Medical Certificate.

In the event the death is an expected or planned home death, a physician familiar with the deceased (without having pronounced the death) can complete the medical certificate of death ***IF*** a "Notification of Expected Home Death Form" is completed.

If physician pronouncing death is not familiar with the deceased, attempts to obtain the medical history should be undertaken in order to provide the most probable circumstances leading to death.

Return to Page 1

Completion of the Medical Certificate can be delegated by the pronouncing physician to a physician more familiar with the deceased's medical history.
An "Interim" Medical Certificate can be provided to the funeral home with as much medical detail as possible. This Certificate should be labelled as "Interim" and a replacement provided to the Vital Statistics Medical Coding Unit as soon as more detail becomes available.

If the death occurred in a Hospice or Palliative Care Unit or designated bed, "Hospice" or "Palliative Care" should be recorded in the place of death section of the certificate.

Completing Part 1

Note: Only one condition should be entered on each line in Part 1.

Line (a) Enter the *immediate cause of death* the disease or complication that led directly to death.

There must always be an entry on line (a). This entry can be the only entry BUT:

Modes of dying, such as heart failure, respiratory failure, renal failure, liver failure, cardiac arrest etc. should be accompanied by a cause on the following line.

Lines (b), (c) and (d): Antecedent causes

If the *immediate cause of death* entered on line (a) was due to, or arose as a consequence of an antecedent disease, enter this condition on line (b).

If the *antecedent cause of death* entered on line (b) was due to, or arose as a consequence of an antecedent disease, enter this condition on line (c) and so on.

Add as many additional lines as are needed to enter the complete sequence of events leading to death. Do not enter in Part II a condition that belongs in the sequence of events leading to death unless you indicate it is a continuation of Part I with (e), (f) (g) etc.

If the *immediate cause of death* entered on line (a) arose as a complication of medical care, enter this medical care on line (b) and enter the condition necessitating the medical care on line (c). Line (d) is used if an additional line is needed to enter the complete sequence of events leading to death.

Return to Page 1

COMPLICATIONS OF SURGERY

When any one of the conditions listed below is reported as the only entry OR first entry on the lowest used line in Part I, with surgery (within 28 days of death) also reported on the certificate, the condition is coded as a complication of surgery unless:

a) The surgery was performed more than 28 days prior to death.
b) When the surgery was performed for the condition reported.
c) When the condition predates the surgery.
d) A pre-existing condition or disease is reported to have caused the condition.
e) It is stated on the certificate "Not a post-operative complication" or "Not related to the surgery" or similar wording.

If these exceptions do not apply, the underlying cause of death (UCOD) will become the reason for the surgery (even if the reason is located in Part II or within the details of surgery section on the certificate.) If the surgery was performed due to an injury, the mechanism of the injury will become the UCOD. Eg. Pneumonia following hip surgery for a fractured hip (from a fall) = a UCOD of a fall. Even if the fall was due to natural disease, if the disease itself did not directly cause the death, this would be considered a Coroner's case.

Complication List: *(this list is not exclusive)*

Acute renal failure
Aspiration
Atelectasis
Bacteremia
Cardiac arrest
Disseminated intravascular coagulopathy (DIC)
Embolism (any site)
Gas gangrene
Hemolysis, haemolytic infection
Hemorrhage NOS (not otherwise specified)
Infarction (any site)
Infection NOS
Occlusion (any site)
Phlebitis (any site)
Phlebothrombosis (any site)
Pneumonia
Pneumothorax
Pulmonary Insufficiency
Septicemia (any)
Shock
Thrombophlebitis (any site)
Thrombosis (any site)

Completing Part II: Other significant conditions

Enter in Part II, in order of significance, all other diseases or conditions which unfavourably influenced the course of the morbid process, and thus contributed to the fatal outcome, but were not part of the sequence of events directly leading to the death.

Return to Page 1

Some of the specific medical detail on Cause of Death requested for accurate coding according to the International Classification of Diseases – 10th edition:

Infections

Specify:
- acute, subacute, or chronic
- the name of the disease and/or infecting organism, where known (if studies are pending indicate "yes" in the section "May further information relating to death be available later)
- the originating site, if localized; mode of transmission where relevant
- for syphilis, whether primary or secondary, congenital or acquired
- for Human Immunodeficiency Virus (HIV) disease, include specific complication(s) and whether AIDS has been confirmed
- the etiology of Hep B, C and AIDS if known. If was due to a transfusion of blood or blood products, include the reason for the transfusion. Indicate "etiology unknown" if applicable

Neoplasms

Specify:
- the morphological type, if known
- malignant, benign, etc., if not specific to the morphology
- site of origin of primary growths (if not known indicate "unknown primary")
- site(s) of metastases, if known
- acute or chronic when reporting leukemia

Alcohol – related deaths

If a condition is believed to be associated with alcohol abuse, include this information in a "due to" position.

Deaths associated with pregnancy, childbirth, and the puerperium

Specify:
- the nature of disease or complication (maternal or neonatal) leading to death
- Conditions in fetus or infant leading to death (specify whether congenital)
- conditions in mother or of placenta, cord or membranes, if believed to have affected the fetus or infant
- whether delivered by caesarean section
- for deaths associated with immaturity, state length of gestation and/or birthweight
- any birth trauma

End of Life Care Roles - Transition 1

Disease advancement

Key indicator(s) into the Transition: Would not be surprised if client died within the next year.

Material provided in package for transition: Note: MOA will add a package with these documents into the chart once client is identified as requiring a palliative approach to care. Material can be separated by transition.

- Advance Care Plan
- Assessment Tools:
  - Palliative Performance Scale (PPS)
  - Pain and symptom diary
  - Edmonton Symptom Assessment Scale
  - Seniors Assessment Tool
- H&CC Referral Form
- End of Life Care Plan

MOA

- (Prior to any transition) Ensure Advance Care Planning education material is displayed
- "Registry" flagging charts/billing – may occur prior to visit or based on GP visit. Flag chart such that if client of H&CC provider calls into office, that physician is made aware of call.
- Schedule visits monthly or sooner if necessary. Add Recall prompts. Encourage client to rebook for the next month's visit and to keep in regular contact.
- Identify patients that potentially can benefit from a palliative approach to care
  - ☐ Surprise question to identify patients "would you be surprised if this patient died in the next year?"
  - ☐ Missing appointments or unusual behaviour eg. Change in gait or personal care *(hygiene, dressing etc.)*
  - ☐ Repeated hospital or emergency room admissions
  - ☐ Poly-pharmacy Issues
  - ☐ Admissions to long-term care *("why" are they there, not only that they were admitted)*
  - ☐ Changes in ability to care for self
  - ☐ Family Members phoning MOA to inquire about patient
  - ☐ Changes in communication eg. *Family calling instead of patient*
  - ☐ Intuition/Instinct

GP

- Assess, manage pain and symptoms; provide prognosis; using PPS, Seniors Assessment tool and ESAS ongoing review/planning. **IF** Home and Community involved, then ensure MOAs put calls through from them.
- Introduce/hold advance care planning conversations:
  - Identify client's values and beliefs
  - May help client identify substitute decision maker (SDM) and review with SDM their role.
  - Clarify illness trajectory, possible complications, prognosis and expected outcomes of treatment to inform goals of care and decisions in advance of a medical crisis (Counselling Fee 0120)
- Introduce self-assessment tools as appropriate to client need. Where applicable, request MOA to support client on these tools (Office Visit 0100, possibly Counselling Fee 0120)
- Follow up with client to confirm if advance care plan is completed (Office visit 0100)

- Understand which family members are involved with both care giving and healthcare decision making. Convey to the family that support is available, and to communicate their needs as well as information about the client. (Office visit 0100, possibly Counselling Fee 0120)
- Consider others that can extend your medical team to form a full healthcare team. These members can include social workers and family.

Specialist / Consultant

- Identify/diagnose, prognostication, investigations (BCCA)
- Introduce/hold advance care planning conversations

Other Health Care Professionals*
Care Coordinator / Case Coordinator or Home Care Nurse

- Communication with GP if care is being provided and your perspective of client needs given identification of advanced illness and based on anticipated trajectory.
- Seek to understand the GP's perspective for care.
- Connect with family, assess families ability to cope at each visit.
- Provide supportive care and/or wound care if needed.
- May introduce/hold advance care planning conversations. Identify client understanding of illness, wishes and values. Share any advance care planning with the GP.
- Provide client and family with information on relevant community resources

Other Relevant Documentation / Tools

Employer's/Insurance forms, Wills, Power of Attorney

End of Life Care Roles - Transition 2

Decompensation, experiencing life-limiting illness

Key indicator(s) into the Transition: Client prognosis approximately 6 months and PPS 50%. (Eligible for Palliative Care Benefits)

Material provided in package for transition:

- BC Palliative Care Benefits form
- No CPR Order Form
- H&CC Palliative Care Referral Form (in some health authorities)
- Compassionate Care Benefits Form

MOA

- Process referral to H&CC for palliative home care and BC Palliative Care Benefits Program
- Coordination of Care Discussions: Facilitate information exchange with H&CC e.g. fax/phone calls
- Ensure practice has a copy of, or electronic access to, local palliative care clinical practice guidelines

GP

- Assess, manage pain and symptoms; provide prognosis, ongoing review/planning. Ensure MOAs put calls through from H&CC Nursing.
- Consider others that can extend your medical team to form a full healthcare team. These members can include social workers and family.
- Hold coordination of care discussions:
    1. Engage client/family
    2. Phone call with H&CC (Community Conference Fee 14016)
- Discuss separately with both groups:
  - Goals of care at current time and in the future with client/family; include discussion of No CPR; and treatment aligned with goals. Reference earlier ACP. (Palliative Planning Fee 14063 plus Palliative Planning Visit 0100)
- Refer to H&CC Palliative Care Home Team and BC Palliative Care Program. Acknowledge that H&CC/PC referral was received by physician practice.

Specialist / Consultant

- Negotiate shared care with GP, re-evaluate plan of care and interventions based on burden of visits, interventions on client

Other Health Care Professionals*
Care Coordinator / Case Coordinator or Home Care Nurse

- H&CC - Nursing:
    - Assess client/family situation, needs & eligibility; involve appropriate disciplines within H&CC (e.g. OT and Nutritionist), and arrange for supports e.g. medical supplies/equipment
    - Coordination of Care:
        - Communicate to GP what home care is being provided and your perspective of client needs.
        - Establish shared care plan with GP.
        - Follow up with updates on care. (GP can bill 14069 for short phone calls after Palliative Planning Fee has been billed, and 14016 for longer discussions)

  - Refer/provide counselling as needed
  - Communicate care plan to home support agency, if involved; refer to local hospice organization or other community group

- H&CC - Palliative Care Team:
  - Available for consult for complexity, including psychosocial issues, and support with acute changes/symptom management via 24hr on-palliative care call service

- H&CC: Provide client and family with information on relevant community resources

Other Relevant Documentation / Tools

Community Healthcare Resource Directory (CHARD)

Practice Support Program...an initiative of the General Practice Services Committee

Transition 3

Dependency and Symptom Increase

Key indicator(s) into the Transition: Concern about ability to support client at home given increasing care needs

Material provided in package for transition:

- Notification of Expected Death Form

MOA

- Ensure regular contact with family (designated decision maker)
- Confirm if the client/family is receiving H&CC palliative care services and bring to physician attention if not
- Identify the primary H&CC Nurse, health unit, and pharmacy details
- Coordination of care discussions: Schedule palliative care conference meeting
- If GP does home visits, may schedule a home visit alone or preferably in conjunction with Home Care Nurse to discuss plans for care as illness progresses

GP

- Assess, manage pain and symptoms; provide prognosis, ongoing review/planning. Ensure MOAs put calls through from H&CC Nursing.
- Coordination of care discussion:
- Either joint visit (0103) or phone call (14016) with H&CC Nursing re options for care as illness progresses (PALLIATIVE CARE PLANNING CONFERERNCE).
- Have self/client/family sign no CPR order form (Counselling Fee 0120 may also be done at Home Visit 0103
- Review with client/family how to contact GP after hours and review with the family if death should occur at home (Office Visit 0100 or Home Visit 0103)
- GP may complete Notification of Expected Death if appropriate. (Involves a discussion with H&CC, as such Community Conferencing Fee 14016 applies)
- Consider others that can extend your medical team to form a full healthcare team. These members can include social workers and family.

Specialist/Consultant

- Specialists: Assess level of input needed, demitting point, re-evaluate intervention

Other Health Care Professionals*
Care Coordinator/Case Coordinator or Home Care Nurse

- H&CC - Nursing: Participate in palliative care planning conference with GP, review goals of care and update the shared care plan (e.g. as to role of further investigations)
- H&CC - Nursing: With GP, help client/family identify and select options for care, depending on the community (may be in conjunction with the Specialist Hospice Palliative Care Team
- H&CC - Nursing: Prepare client/family for home death and provide intensive home care/support and specifically home death
- H&CC - Nursing: Assess need for further equipment as illness progresses & function reduced--e.g. hospital bed; also need for increased respite/support from home support

Other Relevant Documentation/Tools

- Home death protocol

Community Healthcare Resource Directory (CHARD)

Team Planning Meeting in Transition 3

Note: Same topics in step #2 will be covered during collaborative phone conversations in transition 2

1. Id team members, including asking client who from the family should be invited to the meeting
2. Hold team planning meeting and discuss the following:

- What other community organizations need to be involved and what other referrals are important
Note: if the client has cancer, other agencies are more likely to be involved
- Disease trajectory and how it is progressing
- Rules of engagement: Will home care nursing need to be involved and if so how (e.g. symptom management, they monitoring), how often will each group visit, how will the team communicate
- Goals of care: client preferences, what quality of life means for client, practical considerations
- Medication reconciliation
- Contacting pharmacist
- Support for client and family

Transition 4

Decline and Last Days

Key indicator(s) into the Transition: Decline and terminal phase

Material provided in package for transition:

- Information on what to expect prior to death and bereavement supports (written materials may be given by H&CC)

MOA

- Ensure regular contact with family (designated decision maker)
- Provide list of local bereavement supports for family
- Expedite calls to physician for dying clients.
- Ensure office has documents for deployment of palliative medication kit used in your area, including pharmacy contact

GP

- Assess, manage pain and symptoms; provide prognosis, ongoing review/planning. Ensure MOAs put calls through from H&CC Nursing.
- Assess abnormal grief, family support (Counselling fee 0120)
- Discuss medications required in home with Home Care nurse; may involve a medication kit (Home visit 0103 plus Community Conf Fee 14016)
- Assess whether client & family are comfortable with their decision re planned location of death; support a change in plan if necessary (Home visit 0103)
- Consider others that can extend your medical team to form a full healthcare team. These members can include social workers and family.

Specialist / Consultant

- Specialists: Provide urgent access if needed For urgent phone advice from specialist (including GP specialist) 14018

Other Health Care Professionals*
Care Coordinator / Case Coordinator or Home Care Nurse

- H&CC - Nursing: Provide on-going assessment of symptoms; Arrange for palliative medication kit or "emergency" medications in the home
- H&CC Nursing: Provide information on what can be expected prior to death and what to do after a death e.g. booklets such as Preparing for the Death of a Love One and When Someone Dies
- H&CC - Nursing: Assess whether client & family are comfortable with their decision re planned location of death; support a change in plan if necessary
- Provide client and family with information on relevant community resources

Other Relevant Documentation / Tools

- "When death is close at hand" (Health authority specific)
- Community Healthcare Resource Directory (CHARD)

Transition 5

Death and Bereavement

Key indicator(s) into the Transition: Death

Material provided in package for transition:

- Death Certificate

MOA

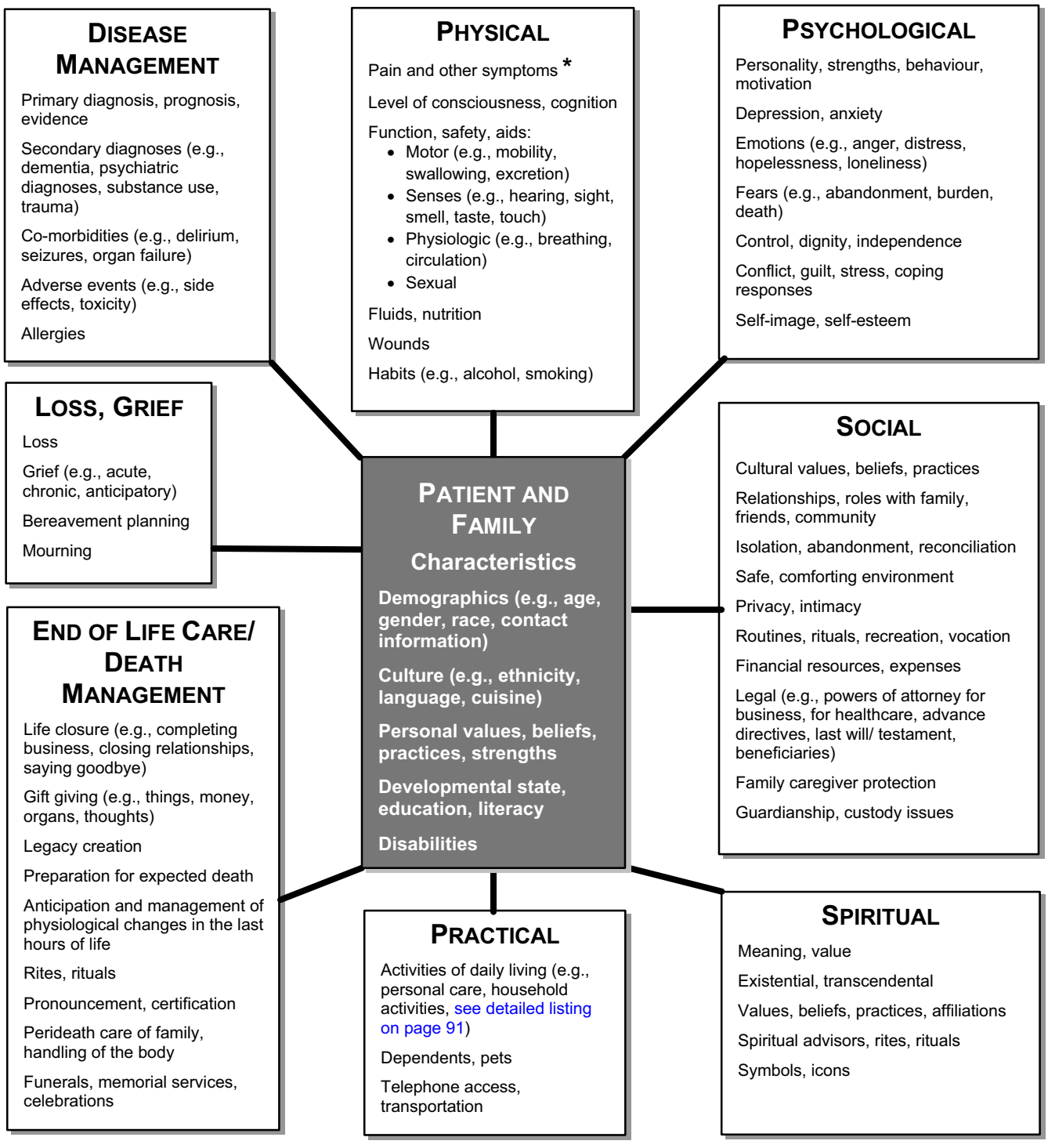
- Ensure regular contact with family (designated decision maker)
- Schedule bereavement calls & send condolence card on behalf of the GP
- Cancel appointments and tests after death; inform specialists.

GP

- May pronounce death
- Assess abnormal grief, family support (Counselling fee 0120)
- Complete death certificate
- Write condolence card and follow up grief and bereavement (Counselling fee 0120)
- Consider others that can extend your team. These members can include social workers and family.

Return to Page 1

Figure #7: Domains of Issues Associated with Illness and Bereavement



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns
Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia
Oral conditions: dry mouth, mucositis
Skin conditions: dry skin, nodules, pruritus, rashes
General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Return to My Voice Table of Contents

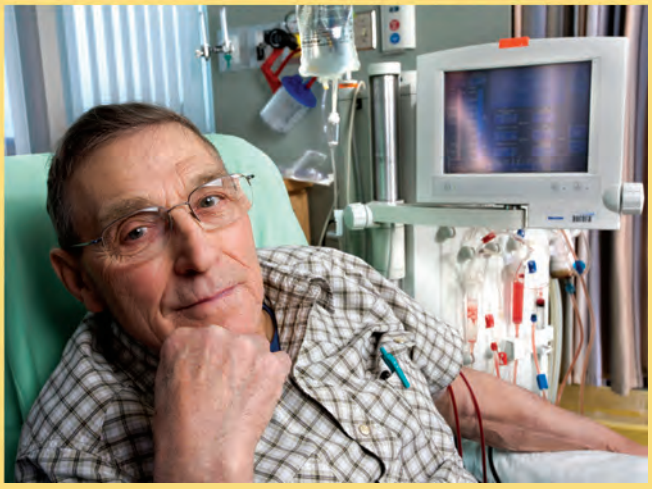
Return to Page 1

Print Whole Document

My Voice

Expressing My Wishes for Future Health Care Treatment

Advance Care Planning Guide



BRITISH COLUMBIA

Next

February 2012

The use of this guide is voluntary and is intended to supplement conversations with your close family or health care providers about the advance care planning options that may be right for you. In addition, the forms provided reflect the law at the date of publication. Laws can change over time. This guide does not replace medical or legal advice.

Library and Archives Canada Cataloguing in Publication

My Voice -- Expressing My Wishes for Future Health Care Treatment.

Includes index.
ISBN 978-0-7726-6524-9

1. Advance directives (Medical care)--British Columbia--Popular works. I. British Columbia. Ministry of Health II. Title.

R726.2 M9 2011 344.71104'197 C2011-909048-1

Health authority document printing reference numbers:

FH: 349976	IH: 807025	NH: 1752
PHSA: PHSA240	VCH: 00089414	VIHA: 90444

Next

Acknowledgements

The Ministry of Health acknowledges Fraser Health for their permission to adapt their My Voice workbook into this new provincial guide for advance care planning. Thanks are also given to the many physicians and patients who shared their time and ideas. The guide was produced by the Ministry of Health in partnership with:

Return to Page 1

Table of Contents

Introduction 2

Why is an Advance Care Plan Important? 3

Developing Your Advance Care Plan 5
- Beliefs, Values and Wishes 5
- Life Support and Life-Prolonging Medical Interventions 6

Advance Care Planning Options 8
- Temporary Substitute Decision Maker (TSDM) 9
- Representation Agreements 11
- Advance Directive 14
- A Representation Agreement and an Advance Directive 16
- Enduring Power of Attorney 19

Changing or Cancelling Your Advance Care Plan 20

Definitions of Terms 22

Putting Your Papers in Order 25

My Advance Care Plan

My Advance Care Plan - Summary 27
- My Temporary Substitute Decision Maker (TSDM) List 28
- My Beliefs, Values and Wishes 30
- My Representative: Standard (RA 7) and Enhanced Agreements (RA 9) 32
  - Representation Agreement (Section 7) 34
  - Form 1: Certificate of Representative or Alternate Representative 40
  - Form 2: Certificate of Monitor 41
  - Form 3: Certificate of Person Signing for the Adult 42
  - Form 4: Certificate of Witnesses 43
  - Representation Agreement (Section 9) 44
- My Advance Directive 50

Resources 52

Wallet Card 52

Next

Introduction

Having a voice in decisions about your health care treatment is important. There may come a time when, due to illness or injury, you are incapable of expressing your treatment wishes to health care providers. By planning in advance, you can be sure that your family, friends and/or health care providers know your wishes, and can ensure these wishes are followed.

New incapacity (or personal) planning legislation came into force in B.C. on September 1, 2011, providing adults with more options for expressing their wishes about future health care decisions. The legislation allows capable adults to put plans into place that outline the health care treatments they consent to or refuse based on their beliefs, values and wishes. If no decision/plan is in place, B.C.'s health care consent legislation gives regulated health care providers specific direction regarding who they must choose to make decisions on a person's behalf.

This guide and workbook pages in the second half of this booklet will help you complete an advance care plan that outlines your wishes about health care decisions in the event you are unable to do so. It will help you consider what is important to you, help you document your beliefs and wishes, and help you develop the advance care plan that best suits you.

Depending on the advance care plan you choose, you may be required to complete legal forms to ensure that your wishes are followed. The guide includes forms that you can complete without the assistance of a lawyer or notary public, which will be legally valid if completed properly. For complex situations, you are encouraged to obtain legal advice to ensure the forms and what you write in them will meet your needs.

Why is an Advance Care Plan Important?

As long as you are capable of understanding and communicating with your doctor, nurse practitioner, registered nurse and/or other health care provider, you will be asked to make your own health care treatment decisions.

However, no one knows what tomorrow will bring. A serious accident or illness can result in you being incapable of making your own health care decisions at the time care is needed. An advance care plan allows for such a possibility. It provides family or close friends and health care providers with a guide to your care and treatment, based on your wishes.

An advance care plan can answer:

- Who do you want to make your health care decisions for you?
- What health care treatment(s) do you agree to, or refuse, if a health care provider recommends them?
- Would you accept or refuse life support and life-prolonging medical interventions for certain conditions?
- What are your preferences should you need residential care and not be able to be cared for at home?

Mary is 54 years old, divorced, likes sports and has two adult children. Two months ago she was struck by a car while riding her bike. She is still unconscious and needs a ventilator to breathe. The doctors say Mary has permanent brain damage and will not recover from her injuries. Even if she wakes up, she will never be able to walk, talk or breathe again on her own. Her daughters have been constantly at her side. Now Mary is fighting infection in both her lungs, is very uncomfortable, and the doctors say Mary may die in a few weeks. They recommend taking Mary off the ventilator and that it would be more comfortable to allow a natural death for Mary. One daughter thinks this is best but the other daughter, who is six months pregnant, wants every possible intervention until Mary's first grandchild is born.

If Mary had shared her wishes for future health care through advance care planning, it would help her daughters and health care providers know more about Mary's beliefs, values and wishes for her health care during this difficult time. It would guide the decisions about care and treatment Mary would make if she could decide for herself.

Advance care planning is about having conversations with your close family, friends and health care provider(s) so that they know the health care treatment you wish to have, or refuse, if you become incapable of expressing your own decisions.

Writing down your beliefs, values and wishes for future health care is an advance care plan. Your advance care plan may also include additional legal documents.

In British Columbia, health care providers are expected to respect an adult's wishes for health care that they expressed while capable. Whether you have expressed your wishes in an advance care plan or not, health care providers will make medically appropriate treatment recommendations for you.

Making an advance care plan lets others know the decisions you would make for yourself, and will give your family and friends the knowledge and tools they need for the future. An advance care plan is a choice. It is a choice that will help alleviate some of the stress your family and friends could face if they are asked to make important health care decisions for you.

Developing Your Advance Care Plan

Beliefs, Values and Wishes

Advance care planning begins by thinking about your beliefs, values and wishes regarding future health care treatment, and talking about them with family or friends, and health care provider(s). When the people you trust know what is important to you with regard to future health care treatment, it is easier for them to make decisions on your behalf.

The following examples may help you figure out what is important to you.

These things make my life meaningful:

- Spending time with my family and friends
- Love for my pet/music/art/garden/work/hobbies/fresh air/sports
- Practising my faith

When I think about what my death could be like, I take comfort in:

- Knowing any pain I have will be treated
- Believing I will have good care and my family continues to be with me
- Believing there is something after death, even if I don't know what

When I think about dying I worry that:

- I may struggle to breathe
- I may have uncontrolled pain
- I might be alone

When I am nearing the end of my life I want:

- My family nearby
- Someone holding my hand
- My religious leader to visit me
- To hear people talking gently about my life's happy memories
- To listen to the music I love
- A window kept open no matter what the weather

Life Support and Life-Prolonging Medical Interventions

Thinking and talking about your wishes for life support and life-prolonging medical interventions is very important, especially if you have a serious or life-threatening illness. Your advance care plan can address different situations, such as your hospital care during and after routine surgery, care in the event of an accident, or end-of-life care decisions.

Physicians and other health care providers will always offer medically appropriate health care based on clinical assessment. Health care providers will want to ensure any symptoms like pain, dizziness, nausea, bleeding or infection are always understood and addressed. As long as you can understand and communicate, your health care provider will explain the medically appropriate care best for you, including any risks, benefits or alternatives. They will also ask if you have any questions and if you wish to accept or refuse the health care treatment.

Some of the hardest decisions deal with the use of life support and life-prolonging medical interventions. Medical interventions can include a ventilator to help with breathing, tube feeding, kidney dialysis, or cardiopulmonary resuscitation to restart the heart and lungs. These treatments are offered when a health care provider believes they are medically appropriate.

The questions below can help you think about the life support or life-prolonging medical interventions you may wish to accept or refuse in future.

If you have a chronic condition:

- What stage is my health condition at and how might it progress?
- Can my condition affect my memory or ability to decide for myself in the future?
- Will it become life-threatening?
- What life support or life-prolonging medical interventions might I need due to this condition?
- What does my health care provider suggest I consider and address in my advance care plan?

If you have a life-threatening illness or injury, do you want to accept or refuse:

- Cardiopulmonary resuscitation (CPR)?
- All, some, or no life support or life-prolonging medical interventions when a health care provider says the health care treatments are medically appropriate?
- A trial period of life support and life-prolonging medical interventions, allowing a natural death to occur if your condition is not going to improve?

You may wish to ask yourself, "Would I want life support or life-prolonging medical interventions if it means I could no longer":

- Enjoy my life and activities the same way I do now?
- Get out of bed, walk or go outside on my own?
- Recognize and communicate meaningfully with my relatives or friends?
- Think for myself?

Advance Care Planning Options

There are a number of options available to communicate your wishes and instructions in the event that you are not capable of doing so yourself. Your personal circumstances, and the type of advance care plan you wish to create will influence the options you choose.

Advance Care Planning Basics

Every advance care plan should consist of these three things:

- Conversations with family or friends and health care providers about your beliefs, values and wishes.
- Writing down your beliefs, values and wishes for future health care treatment.
- Writing down the contact information for the people who qualify to be on your Temporary Substitute Decision Maker list.

Advance Care Planning Options

The following items are optional depending on your advance care planning needs:

Standard Representation Agreement: Section 7	Allows you to name a person to make routine financial management decisions, personal care decisions and some health care decisions. Does not allow the person to refuse life support or life-prolonging medical interventions for you.
Enhanced Representation Agreement: Section 9	Allows you to name a person to make personal care decisions and some health care decisions, including decisions to accept or refuse life support or life-prolonging medical interventions for you.
Advance Directive	Allows you to state your decisions about accepting or refusing health care treatments, including life support or life-prolonging medical interventions, directly to a health care provider. The advance directive must be followed when it addresses the health care decision needed at the time. No one will be asked to make a decision for you.
Enduring Power of Attorney	Allows you to appoint someone to make financial and legal decisions on your behalf if you become incapable.

Temporary Substitute Decision Maker (TSDM)

A temporary substitute decision maker (TSDM) is chosen if you have not legally named an individual (representative) to make health care decisions for you when you are incapable of making them yourself.

The TSDM is chosen by your doctor or other health care provider from a list you can fill out. The order of the people who qualify to be on the list is determined by B.C. law. To be able to act as a TSDM, the person must be 19 or older, be capable, have no dispute with you, and have been in contact with you in the past year.

One person on the list below must be approached in the order given:

1. Your spouse (married, common-law, same sex - length of time living together doesn't matter)
2. A son or daughter (19 or older, birth order doesn't matter)
3. A parent (either, may be adoptive)
4. A brother or sister (birth order doesn't matter)
5. A grandparent
6. A grandchild (birth order doesn't matter)
7. Anyone else related to you by birth or adoption
8. A close friend
9. A person immediately related to you by marriage (in-laws, step-parents, step-children, etc.)

You may not change the order of the list. A person lower down on the list may only be chosen as your TSDM by your health care provider if all the people above them do not qualify or are not available.

If you know that you want someone lower on the list to make your health care decisions, then you should name that person legally as your representative using a representation agreement form. There are two different types of representation agreement forms at the back of this guide. Be sure to use the one that meets your needs. More information on the differences between these two types of representation agreement follows in the next section.

Your TSDM is legally required to make decisions that respect your wishes. If you have had discussions about advance care planning and written down your beliefs, values and wishes, your TSDM will know and be able to speak to your wishes when asked to make health care treatment decisions for you.

If you are happy with a TSDM being chosen in the event one is needed, your advance care plan will consist of the following:

- Discussing your beliefs, values and wishes with close family or a trusted friend;
- Writing down your beliefs, values and wishes (p.30); and
- Filling out your TSDM list (p.28) with the contact information of people who may be approached, in order, by a health care provider if a TSDM is needed.

Pat, 47, is an office worker in good health who lives in a small northern town. She has been married to Tom, 49, for 24 years and they have three children aged 20, 17 and 14. The two youngest live at home and the eldest moved away last year to attend college. After losing a number of family and friends over the past few years, Pat began to think about her future health care decisions. She spoke about her feelings and concerns with Tom. It turned out Tom was having many of the same thoughts as Pat. Together they decided to do advance care planning so that each would know the other's wishes for future health care decisions.

Pat and Tom chose to document their beliefs, values and wishes and simply fill out their TSDM lists because:

- Pat and Tom are in a long term, stable relationship;
- They trust each other to make good decisions for each other by honouring their beliefs, values and wishes;
- As spouses, they are at the top of each other's TSDM list; and
- Pat has discussed her beliefs, values and wishes with her adult child and her mother, who would qualify as the two next TSDMs if Tom is not available.

Representation Agreements

Adults in British Columbia may name a representative in a representation agreement if they want a specific person to make certain types of decisions on their behalf. There are two types of representation agreements.

Standard Agreement: Section 7 Representation Agreement

A section 7 representation agreement allows you to name a representative to make decisions about the routine management of your financial affairs, your personal care, and some health care treatment decisions. It does not allow your representative to make health care treatment decisions for you that involve refusing life support or life-prolonging medical interventions.

A standard agreement may be an option for adults who are assessed by a health care provider as being incapable of making an enhanced (section 9) representation agreement. A section 7 representation agreement allows adults with lower levels of capability (e.g., due to some developmental disabilities or injuries/illnesses of the brain that affect cognitive ability) to do some advance care planning.

Adults who have the capability to make a section 9 representation agreement may choose to make a section 7 representation agreement if it addresses their needs.

Completing a section 7 representation agreement as part of your advance care plan involves the following:

- Discussing your beliefs, values and wishes with close family or a trusted friend;
- Writing down your beliefs, values and wishes (p.30);
- Naming your representative and writing down your instructions in a representation agreement, using a section 7 form (p.34); and
- Filling out your TSDM list with the contact information of people who may be approached by a health care provider if a TSDM is needed, in the event your representative resigns or is unavailable, or a decision about life support or life-prolonging medical interventions is required (p.28).

Michael, 38, was in a serious motorcycle accident 10 years ago. He suffered a head injury, became paralyzed and has ongoing memory problems as a result of the accident. He is single, his parents are deceased, and he has one younger brother he is close to who lives outside the province. Michael has been living alone in his own apartment for the last eight years. Specialized equipment and visiting home support workers enable him to be as independent as possible. His best friend, Ben, takes him shopping every week and to medical appointments. Michael's health has been good although he says his memory has worsened in the last year, making decision-making difficult. He has become increasingly dependent on Ben to ensure his bills are paid on time and to schedule and attend his medical appointments with him. Michael's community nurse has suggested he name a representative to help him manage his personal, financial and some health care decisions.

Michael is eligible to complete a section 7 representation agreement because, in consideration of all relevant factors, he:

- Can communicate his desire to have a representative to help him make decisions about his personal care, routine finances and some health care, and he understands that his representative may make, or stop making, decisions that will affect him;
- Trusts his friend Ben and knows Ben cares about him;
- Knows and understands that he does not want Ben to make decisions about refusing life support or life-prolonging medical interventions;
- Ben qualifies and has agreed to be named as his representative; and
- Although his brother lives outside B.C., he does stay in touch and would qualify as Michael's TSDM if health care decisions were needed about life support.

Enhanced Agreement: Section 9 Representation Agreement

A section 9 representation agreement allows you to name a representative to make decisions about personal care and health care treatments, including decisions about accepting or refusing life support and life-prolonging medical interventions. A representative named in a section 9 representation agreement may not make decisions about your financial matters. In order for someone to make financial decisions for you in the event you become incapable, you can appoint a person (called an attorney) using an enduring power of attorney form (see p.19 for more information).

Completing a section 9 representation agreement as part of your advance care plan involves the following:

- Discussing your beliefs, values and wishes with close family or a trusted friend;
- Writing down your beliefs, values and wishes (p.30);
- Naming your representative and writing down your instructions in a representation agreement, using a section 9 form (p.44); and
- Filling out your TSDM list with the contact information of people who may be approached by a health care provider if a TSDM is needed, in the event your representative resigns or is unavailable (p.28).

Gurdeep, 74, moved to Canada 10 years ago with his wife Rani, who speaks little English. Gurd's health has been poor for seven years. He has kidney disease, diabetes and high blood pressure. He needs kidney dialysis three times a week, and has congestive heart failure that worsens every few months. He and Rani live with their oldest son, Jeet, who helps with his care and goes to Gurd's doctor's appointments with him. Gurd has five other children who live nearby, and has a good relationship with all of them. As Gurd's health is clearly declining, his doctor suggests he do advance care planning so that his wishes are known and it is clear who will make decisions for Gurd if he becomes incapable of deciding for himself.

Gurd talked with his wife and children, and identified that he would prefer to stay at home to the end of his life, rather than in hospital or a residential care facility. He worries about being in pain, and would not want to be hooked to machines to prolong his life. Despite his health concerns, he would also like to be an organ donor. He decides that he would like Jeet to make health care treatment decisions for him, if he is incapable.

Gurd chose to complete a section 9 representation agreement because:

- Jeet is not at the top of the TSDM list and must be named as Gurd's representative in order to be asked to make his health care decisions;
- Gurd knows Jeet can talk easily with his doctor without a translator;
- Gurd trusts Jeet will make health care treatment decisions that honour his beliefs, values and wishes, and that he will include Rani in important conversations; and
- A section 9 representation agreement will allow Jeet to accept or refuse life support and life-prolonging medical interventions.

Gurd may wish to name one of his other children as his alternate representative in case Jeet resigns. In addition, or alternatively, Gurd could make an advance directive, noting on the section 9 representation agreement form that his advance directive may be followed directly by a health care provider without his representative being asked to decide. These options would ensure Gurd's wishes and instructions for health care treatments are followed.

Advance Directive

An advance directive allows a capable adult to clearly state their decisions about accepting or refusing health care treatments, including life support and life prolonging medical interventions, and provides those instructions and decisions directly to a health care provider(s). Your advance directive must be followed as long as it addresses the health care treatment you need at the time. A TSDM will be chosen only when a health care treatment decision is needed that is not addressed by your advance directive.

Completing an advance directive as part of your advance care plan involves the following:

- Discussing your beliefs, values and wishes with close family or a trusted friend;
- Writing down your beliefs, values and wishes (p.30);
- Outlining your decisions for future health care treatment in an advance directive (p.50); and
- Filling out your TSDM list with the contact information of people who may be approached by a health care provider if a TSDM is needed to make a health treatment decision which is not addressed in your advance directive (p.28).

Jenny, 58, moved to Canada 24 years ago from China. She is unmarried with no close family. She is a private person with a cat and a small group of friends, including her close friend Rose who travels frequently. Jenny has been healthy all her life until one month ago when she felt strong chest pains while walking up a steep hill. After several tests, Jenny's doctor said her arteries are becoming blocked, her cholesterol is too high, and she is at serious risk of a heart attack. He prescribed medication for her condition, suggested she quit smoking and referred her to a heart specialist for further care. He suggested she think about doing advance care planning to ensure her health care decisions are known and respected by her health care providers since she has no close family. After thinking over what life support and life-prolonging medical interventions she might need if her condition worsens, Jenny chose to make an advance directive.

Jenny chose to complete an advance directive because:

- Jenny does not have any family and her close friend may not be available for a health care provider to choose as her TSDM;
- Jenny can set out her wishes and instructions for life support and life-prolonging medical interventions and when she may want them to be started, continued or stopped; and
- Jenny's doctor knows Jenny and her hopes and wishes for the future much better after having an advance care planning conversation with her, and having a copy of her advance directive.

Jenny may wish to talk with her friend Rose or someone else she trusts about her wishes, and ensure they are identified in her list of contacts to act as TSDM if needed. She may also wish to make an enduring power of attorney to provide for someone to manage her finances and property if she becomes incapable of doing so herself (see p.19 for more information).

A Representation Agreement and an Advance Directive

Different personal circumstances may influence whether an adult chooses to make a representation agreement, an advance directive, or simply to discuss their beliefs, values and wishes with close family and friends and identify contact information for a TSDM. British Columbia's personal planning laws also provide the option of choosing to have both a representation agreement and an advance directive.

If you have both a representation agreement and an advance directive, and want your advance directive to be followed by your health care provider without your representative being asked for a decision, then you must state this in your representation agreement.

Completing a representation agreement and an advance directive as part of your advance care plan involves the following:

- Discussing your beliefs, values and wishes with close family or a trusted friend;
- Writing down your beliefs, values and wishes (p.30);
- Naming your representative in a representation agreement using a section 7 (p.34) or section 9 (p.44) form;
- Outlining your decisions for future health care treatment in an advance directive (p.50) [note: you will need to state in your representation agreement that a health care provider may act in accordance with the instructions in your advance directive without the consent of your representative if this is your wish]; and
- Filling out your TSDM list with the contact information of people who may be approached by a health care provider when a TSDM is needed to make a health treatment decision if your representative resigns or is unavailable and your advance directive does not apply (p.28).

A Section 7 Representation Agreement and an Advance Directive

Making an advance directive in addition to a section 7 representation agreement provides specific instructions directly to your health care provider(s), as long as you write in your representation agreement that your advance directive may be acted on without your representative being asked to make health care decisions for you.

Marie, 34, was diagnosed and treated for early psychosis when she was 16. Most of the time she functions well, manages her symptoms, and can look after herself. She is married to Tony, who works away from home periodically. Her sister, Jeanne, lives nearby and helps Marie whenever she can. When Marie is unwell, it is usually due to recurring symptoms of psychosis. When this happens, she becomes incapable of looking after herself and her home. Assessment and treatment of her symptoms may be done at home, but at other times she is admitted to an inpatient psychiatric unit at the local hospital. This cycle has repeated itself every year or two, and when Marie's symptoms are severe, she sometimes refuses the treatment that can make her stable.

After her last stay in hospital, Marie spoke with Tony, her psychiatrist and Jeanne about longer-term planning for her care during these events. On her last visit, Marie's family doctor suggested she do advance care planning to make future health care treatment and personal planning decisions. It was suggested that Marie name a representative to ensure her care and routine financial needs are looked after if she needs to be in hospital and Tony is not home. She was also advised to make an advance directive to ensure that she is treated as early as possible whenever her symptoms of psychosis recur. Marie chose to make a section 7 representation agreement and an advance directive.

Marie chose to complete a section 7 representation agreement and an advance directive because:

- Marie's representative, Jeanne, will be able make decisions about Marie's routine finances when she is ill and Tony is away. Marie may limit Jeanne's authority to make health care decisions to only those times when the symptoms of psychosis reach a particular stage.
- Marie does not want Jeanne to make decisions to refuse life support.
- Marie's advance directive allows her to provide detailed instructions for her own health care directly to her health care provider(s).
- An advance directive will ensure Marie gets the medically appropriate care she requires, even if she refuses the treatment at the time the care is needed.

A Section 9 Representation Agreement and an Advance Directive

Making an advance directive in addition to a section 9 representation agreement provides specific instructions directly to your health care provider(s), as long as you write in your representation agreement that your advance directive may be acted on without your representative being asked to make health care decisions for you.

Don, 68, is a businessman who found out two months ago that he has prostate cancer. Don has no other health concerns – although he has smoked cigarettes for over 50 years, has a chronic cough and is a little overweight. He lost a friend to prostate cancer last year and his brother died from colorectal cancer five years ago. Don has been divorced twice, has three adult daughters who live in the same city, is still close friends with his first wife, and moved in two months ago with his new partner Sheila, whom his daughters don't know well. He gets along well with his youngest daughter, Karen and she knows his wishes. Don visited his doctor for a routine test and discussed his concerns. His doctor suggested he think about advance care planning and consider who his decision- maker would be if he is incapable of making his own health decisions. Don chose to make a section 9 representation agreement and an advance directive.

Don chose to complete a section 9 representation agreement and an advance directive because:

- Don has more than one close relationship with many people who care deeply for him. If Don becomes ill and incapable of deciding for himself, there is a possibility that many people may believe they can best express Don's wishes.
- Without a named representative, Don's health care providers must choose Sheila as TSDM to decide, which may concern his daughters.
- By setting out his instructions for health care in an advance directive, Don's health care provider(s) will know his wishes.

If Don wants his first wife and/or his youngest daughter Karen to be his representative(s), he may name one as his representative and one as his alternate.

Enduring Power of Attorney

An enduring power of attorney allows an adult to appoint another person (called their attorney) to make decisions regarding their financial and legal affairs. The person (attorney) is authorized to act when the adult becomes incapable.

The powers provided to the attorney can be tailored to suit your needs. For example, this may range from the ability to deposit cheques into your chequing account to complete access to all of your assets.

Attorneys may not make health care treatment decisions. A representation agreement is the only way to appoint someone to act on your behalf for health care treatment decisions.

Resources

The enduring power of attorney form can be found at: www.ag.gov.bc.ca/incapacity-planning/pdf/Enduring_Power_of_Attorney.pdf

More information can be found on the Public Guardian and Trustee of British Columbia website at: www.trustee.bc.ca

The Lawyer Referral Service (www.cba.org/BC/Initiatives/main/lawyer_referral.aspx) is operated by the Canadian Bar Association's British Columbia branch. It offers an initial consultation with a lawyer for up to 30 minutes for a small fee. Operators are available 8:30 am to 4:30 pm, Monday to Friday. Phone 604 687-3221 in the Lower Mainland or toll-free in B.C. at 1 800 663-1919.

Changing or Cancelling Your Advance Care Plan

Your personal circumstances change over time. As long as you are capable, you can change or cancel (revoke) your advance care plan at any time. This includes representation agreements and advance directives.

It is important to regularly review and make changes to your advance care plan when you believe it is necessary. During a review, ask your representative or possible TSDM if they are still willing and able to make health care treatment decisions for you. Review the wishes you wrote in your advance care plan, including any specific instructions you wrote in your representation agreement or advance directive.

Before changing or cancelling your advance care plan, be sure you have up-to-date knowledge about your current health condition and any new health care treatments available to you.

The instructions below tell you what to do if you want to change and update, or cancel your advance care plan, including your representation agreement or advance directive if you made them.

1. Changes to your advance care plan summary, TSDM contact list and/or beliefs, values and wishes for health care, including life-prolonging medical interventions:

   Destroy the old pages and fill out new ones. Be sure to sign and date your new pages where required. If you did not name a representative or make an advance directive before and still do not want to, skip to 4.

   If you want to name a representative [section 7 (p.34) or section 9 (p.44)] or make an advance directive (p.49), complete the forms and inform your family, friends and health care providers.

2. Changes to your representation agreement (section 7 or 9) and/or advance directive
   You have two options:
   - Make the changes directly in your existing representation agreement or advance directive and then sign and date them in front of witnesses in the same manner as you did the originals, or
   - Create a new representation agreement or advance directive to replace the old ones and cancel your old representation agreement or old advance directive (see 3).

3. Cancelling an existing representation agreement or advance directive
   To cancel (revoke) an existing representation agreement or advance directive you must:
   - Destroy the original or make another document and express your intention to cancel the old one; and
   - Give a written notice of the cancellation (revocation) to the person named as your representative, including any alternate representative or monitor.

4. Notification of changes
   After changing or cancelling your advance care plan, you should:
   - Inform any family, friends and health care providers you have changed or cancelled your advance care plan, including changes to your representation agreement or advance directive if you completed the forms.
   - Ask your family, friends, representative (if you have one), and health care providers to give you back the old copies of your advance care plan, including copies of your old representation agreement and advance directive if relevant, so you can destroy them.
   - Provide copies of your newly changed advance care plan, including representation agreement and advance directive (if you completed them), to your close family or friend, and health care provider(s).
   - It is important to ensure that your physician and other health care providers are aware of your most up-to-date wishes and instructions about your care. Please ensure that if you update your advance care plan, including your representation agreement or advance directive, that you advise all relevant health care providers. Be sure to ask them to review and update or cancel as appropriate any medical orders that no longer apply.

Definitions of Terms

Advance care plan is a written summary of a capable adult's wishes or instructions to guide a substitute decision maker if that person is asked by a physician or other health care provider to make a health care treatment decision on behalf of the adult.

Advance care planning is a process by which a capable adult talks over their beliefs, values and wishes for health care with their close family/friend(s) and a health care provider in advance of a time when they may be incapable of deciding for themselves.

Advance directive is a capable adult's written instructions that speak directly to their health care provider about the health care treatment the adult consents to, or refuses. It is effective when the capable adult becomes incapable and only applies to the health care conditions and treatments noted in the advance directive.

Allow a natural death is when the patient receives medically appropriate care for symptoms, such as pain or shortness of breath, as death approaches.

Cardiopulmonary resuscitation (CPR) is an emergency procedure used to revive someone when their heart and/or lungs stop working unexpectedly. CPR can include repeated compressions to the person's chest and rescue breathing to inflate the person's lungs and provide oxygen.

Dialysis is a medical intervention that cleans a person's blood when their kidneys can no longer do so.

End-of-life care is provided in the final stage of life. Care provided during this time may be called supportive care, palliative care or symptom management. End-of-life care addresses physical, psychological, and spiritual concerns and focuses on comfort, respect for decisions, and support for the family. It is provided by an interdisciplinary group of health care providers.

Enduring power of attorney is a document in which an adult authorizes another person (called their attorney) to make decisions in relation to the adult's financial affairs, business and property. The person (attorney) is authorized to act when the adult becomes incapable, or to continue to act when the adult remains incapable. Attorneys may not make health care treatment decisions.

Health care provider is a professional licensed, certified, or registered to provide health care under the *Health Professions Act* (e.g., physician, nurse practitioner, registered nurse) and *Social Workers Act*.

Health care treatment is anything done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health care purpose and may be a series of similar treatments or care (e.g., administration of blood pressure pills, wound care) given over time or a plan for a variety of care purposes for up to one year.

Incapable (incapability) is determined by a health care provider who must base their decision on whether or not the adult demonstrates that they understand:

1. The information given about their health condition;
2. The nature of the proposed health care including risks, benefits and alternatives; and
3. That the information applies to their situation.

Life support and life-prolonging medical interventions are health care treatments like tube feedings, ventilators (breathing machines), kidney dialysis, medications, and cardiopulmonary resuscitation. They are considered medically appropriate care when the goal of care is to continue or prolong life.

Medically appropriate care is health care treatment offered by a health care provider that is consistent with the patient's condition and goals of care, based on the health care provider's health assessment.

Monitor is a person that may be appointed in a representation agreement to ensure the representative carries out his/her duties.

Nurse practitioner is a registered nurse who has met the requirements of the profession to be registered and to use the title of nurse practitioner. They provide expanded nursing services including diagnosing, prescribing, ordering tests and managing common acute illnesses and chronic conditions.

Personal guardian (committee of the person) is a person appointed by the court to make health and personal decisions for the benefit of the adult when they are incapable of deciding on their own.

Personal care refers to the daily living needs of individuals, such as living arrangements, diet, clothing, hygiene, exercise, and safety.

Power of attorney is a document that appoints a person (called an attorney) who is authorized by a capable adult to make financial, business and/or property decisions on their behalf. Attorneys may not make health care treatment decisions.

Representative is a person 19 years or older who is named by a capable adult, in a representation agreement, to make health care treatment decisions on their behalf when they are incapable of deciding.

Representation agreement (RA) is the document in which a capable adult names their representative to make health care and other decisions on his/her behalf when incapable. There are two types:

1. Section 7 RA: Adult may authorize a representative to make decisions about the routine management of financial affairs, personal care and some health care decisions on behalf of the adult, excluding decisions about the refusal of life support and/or life-prolonging medical interventions.
2. Section 9 RA: Adult may authorize a representative to make personal care and health care decisions on behalf of the adult, including decisions about the acceptance or refusal of life support and life-prolonging medical interventions.

Spouse is a person who:

a. is married to another person, and is not living separate and apart, within the meaning of the *Divorce Act* (Canada), from the other person; or
b. is living and cohabiting with another person in a marriage-like relationship, including between persons of the same gender.

Substitute decision maker is a capable person with the authority to make health care treatment decisions on behalf of an incapable adult, and includes a personal guardian (committee of the person), representative and/or temporary substitute decision maker.

Temporary substitute decision maker (TSDM) is a capable adult chosen by a health care provider to make health care treatment decisions on behalf of an incapable adult when care is needed. A TSDM is not chosen if the adult has an advance directive that addresses the care needed at the time, or if the adult has an available personal guardian or representative.

Tube feeding is a method of providing nutrition to a person who cannot eat using their mouth. Tube feedings involve the temporary or permanent placement of a tube that is used for liquid food, either through the person's nose or into their stomach through the abdominal wall.

Ventilator is a machine used to provide air into and out of the lungs when a person is not able to breathe on their own.

Putting Your Papers in Order

Advance care planning is a good time to put all of your personal planning papers together where they can be easily found. This will help those you have put in charge of your affairs to find them if needed. Read the list below and fill in the boxes and lines that apply to you.

I am an organ donor (register at www.transplant.bc.ca): ❑ Yes ❑ No

I have appointed an attorney under a power of attorney: ❑ Yes ❑ No

Name of attorney: _____

I have appointed an attorney under an enduring power of attorney: ❑ Yes ❑ No

Name of attorney: _____

Where to find my power of attorney and/or enduring power of attorney documents:

_____

I have a will: ❑ Yes ❑ No

Where to find my will: _____

I have a lawyer: ❑ Yes ❑ No

Name of lawyer: _____ Phone: _____

I have a life insurance policy: ❑ Yes ❑ No

Company: _____

I have made funeral and burial/cremation arrangements: ❑ Yes ❑ No

Company: _____ Phone: _____

Other papers:

_____

_____

_____

_____

My Advance Care Plan

This section provides all of the necessary tools and forms you need to develop your advance care plan. Instructions at the top of each page will help you determine which pages you need to fill out. The pages have been designed so you can tear off the ones you need.

Only fill out the pages you need for the legal documents you choose. If needed, refer back to the descriptions of the different advance care plan options in the first part of this guide to help you decide what documents you need to fill out for your future health care needs.

Next

My Advance Care Plan - Summary

This summary is the cover of your advance care plan.

Full name (please print): _____ Signature: _____

Date this advance care plan was completed: _____
dd/mm/yyyy

This is an update of my advance care plan: ❑ Yes ❑ No

My advance care plan includes (tick all that apply):

- ❑ My beliefs, values and wishes
- ❑ My TSDM list
- ❑ My standard representation agreement (section 7) **- optional**
  - ❑ Form 1 - Certificate of Representative or Alternate Representative
  - ❑ Form 2 - Certificate of Monitor
  - ❑ Form 3 - Certificate of Person Signing for the Adult
  - ❑ Form 4 - Certificate of Witnesses
- ❑ My enhanced representation agreement (section 9) **- optional**
- ❑ My advance directive form **- optional**

I have given copies of this advance care plan to:

_____ Relationship to me: _____ Phone: _____

_____ Relationship to me: _____ Phone: _____

_____ Relationship to me: _____ Phone: _____

_____ Relationship to me: _____ Phone: _____

_____ is my health care provider. Phone: _____

My Temporary Substitute Decision Maker (TSDM) List

If needed, this list will be used by your health care provider(s) to choose a TSDM for you. The order of the people on the list is set out in B.C. law and may not be changed.

To qualify as a TSDM, the person listed must be 19, capable, have no dispute with you, and have been in contact with you in the year before you need the health care. If a TSDM is needed to make a health care decision for you, your health care provider will choose the first person on the list who is qualified and available. If you want to specify one person to make health decisions for you, you must fully complete either a standard (p.34) or enhanced (p.44) representation agreement.

Spouse (includes married, common-law, same-sex - length of time living together does not matter)

Name	Phone

Children (any - birth order does not matter)

Name	Phone	Name	Phone

Parents (either - may include adoptive)

Name	Phone	Name	Phone

Brothers or Sisters (any - birth order does not matter)

Name	Phone	Name	Phone

Grandparents (any)

Name	Phone	Name	Phone

Grandchildren (any - birth order does not matter)

Name	Phone	Name	Phone

Anyone else related to me by birth or adoption

Name	Phone	Name	Phone

Close friend

Name	Phone	Name	Phone

A person immediately related to me by marriage (ranked equally)

Name	Phone	Name	Phone

I know a TSDM will not be chosen to make health care decisions for me if I complete an optional representation agreement form and/or an advance directive form which addresses the health care condition I have when the care is needed. I also know a TSDM will be chosen to make health care decisions for me if I have no representative, if my representative is unavailable, or if my optional representation agreement and/or advance directive does not address the health care condition I have

☐ I agree.

Name (print)	Signature	Date signed

My Beliefs, Values and Wishes

Complete this page for all advance care plans, regardless of whether you choose to complete a representation agreement form or advance directive form. If needed, this information will help your substitute decision maker (court appointed personal guardian, representative or TSDM) make future health care treatment decisions for you.

Note: If you want to make an advance directive or name a representative in a representation agreement with specific instructions about your health care treatment decisions, be sure to write your instructions directly on those forms. The information you write on these pages is not a representation agreement or an advance directive.

My beliefs (what gives my life meaning)

My values (what I care about in my life)

My wishes (for future health care treatment, life support and life-prolonging medical interventions)

Name (print)	Signature	Date signed

My Representative - Standard Agreement (section 7)

Section 7 Representation Agreement Form (p.34-39)

Use a section 7 form **if you want** your representative to be authorized to make decisions about your routine financial affairs, your personal care and some health decisions.

A section 7 form does not provide a representative with the authority to refuse life support and life-prolonging medical interventions.

In addition to a Section 7 Representation Agreement form, the following certificates must be completed (if they apply) for the agreement to be effective:

- Form 1: Certificate of Representative or Alternate Representative (p.40)
- Form 2: Certificate of Monitor (p.41)
- Form 3: Certificate of Person Signing for the Adult (p.42)
- Form 4: Certificate of Witnesses (p.43)

My Representative - Enhanced Agreement (section 9)

Section 9 Representation Agreement Form (p.44-49)

Use a section 9 form **if you want** your representative to be authorized to make decisions about accepting or refusing life support and life-prolonging medical interventions on your behalf, in addition to other health and personal care decisions.

REPRESENTATION AGREEMENT (SECTION 7)

Print

Made under Section 7 of the *Representation Agreement Act*.

The use of this form is voluntary. Be advised that this form may not be appropriate for use by all persons, as it provides only one option of how a Representation Agreement may be made. In addition, it does not constitute legal advice. For further information, please consult the *Representation Agreement Act* and Representation Agreement Regulation or obtain legal advice.

This form reflects the law at the date of publication. Laws can change over time. Before using this form, you should review the relevant legislation to ensure that there have not been any changes to the legislation or section numbers.

The notes referenced in this Representation Agreement are found at the end of this Agreement and are provided for information only.

1. THIS REPRESENTATION AGREEMENT IS MADE BY ME, THE ADULT:

Full Legal Name of the Adult	Date (YYYY / MM / DD)
Full Address of the Adult	

2. REVOCATION OF PREVIOUS REPRESENTATION AGREEMENTS

I revoke all previous Representation Agreements granting authority under section 7 of the *Representation Agreement Act* made by me.

(See Note 1 – actions that must be taken to revoke a previous Representation Agreement)

(See Note 2 – effect of revocation on a previous section 7 Representation Agreement)

3. REPRESENTATIVE

(See Note 3 – naming a Representative)

I name the following person to be my Representative:

Full Legal Name of Representative
Full Address of Representative

4. ALTERNATE REPRESENTATIVE (OPTIONAL)

(See Note 3 – naming a Representative)

(Strike out this provision if you do not want to appoint an Alternate Representative.)

If my Representative

- dies,
- resigns in accordance with the *Representation Agreement Act*,
- is my spouse, as defined in the *Representation Agreement Act*, at the time that I make this Representation Agreement, and our marriage or marriage-like relationship subsequently terminates as set out in the *Representation Agreement Act*, or
- becomes incapable,

then I name the following person to be my Alternate Representative:

Full Legal Name of Alternate Representative
Full Address of Alternate Representative

5. EVIDENCE OF AUTHORITY OF ALTERNATE REPRESENTATIVE

(See Note 4 – statutory declaration for evidence of authority of Alternate Representative)
(Strike out this provision if you are not appointing an Alternate Representative.)

A statutory declaration made by my Representative, my Alternate Representative (if one is named), or the Monitor (if one is named), declaring that one of the circumstances referenced in section 4 of this Representation Agreement has occurred, and specifying that circumstance, is sufficient evidence of the authority of my Alternate Representative to act in place of my Representative.

6. AUTHORITY OF REPRESENTATIVE

(See Note 5 - what a Representative may and may not be authorized to do under a section 7 Representation Agreement)

Pursuant to section 7 of the *Representation Agreement Act*, I authorize my Representative to:
(If you want your Representative to have both types of authority, do not strike out either of the following provisions. If you want your Representative to have authority over only one of the following matters, strike out the provision over which you do not want your Representative to have authority. You may not strike out both types of authority.)

a. help me make decisions
b. make decisions on my behalf

about the following:
(Strike out any of the following matters for which you do not want your Representative to have authority.)

a. my personal care;
b. the routine management of my financial affairs, as set out in the Representation Agreement Regulation;
c. major health care and minor health care, as defined in the *Health Care (Consent) and Care Facility (Admission) Act*;
d. obtaining legal services for me and instructing counsel to commence proceedings, except divorce proceedings, or to continue, compromise, defend or settle any legal proceedings on my behalf.

7. MONITOR

(See Note 6 - what a Monitor is and whether one is required)

(Strike out this provision if a Monitor is not required and you do not want to name a Monitor.)

I name the following person as Monitor of this Representation Agreement:

Full Legal Name of Monitor
Full Address of Monitor

8. EFFECTIVE DATE

This Representation Agreement becomes effective on the date it is executed.

9. SIGNATURES

ADULT AND WITNESS SIGNATURES

ADULT'S SIGNATURE

- The Adult must sign and date in the presence of both Witnesses.

Signature of Adult	Date Signed (YYYY / MM / DD)
Print Name	

WITNESSES TO ADULT'S SIGNATURE

(See Note 7 – information for witnesses)

WITNESS NO. 1

- Witness No. 1 must sign in the presence of the Adult and Witness No. 2.

Signature of Witness No. 1	Date Signed (YYYY / MM / DD)
Print Name	
Address	
If witness is a lawyer or member of the Society of Notaries Public of British Columbia, check relevant box below: ☐ lawyer ☐ member of the Society of Notaries Public of British Columbia	

WITNESS NO. 2

- Not required if Witness No. 1 is a lawyer or member in good standing of the Society of Notaries Public of British Columbia.
- Witness No. 2 must sign in the presence of the Adult and Witness No. 1.

Signature of Witness No. 2	Date Signed (YYYY / MM / DD)
Print Name	
Address	

REPRESENTATIVES' SIGNATURES

(See Note 8 - when a Representative may exercise authority under this Representation Agreement)

REPRESENTATIVE

Signature of Representative	Date Signed (YYYY / MM / DD)
Print Name	

ALTERNATE REPRESENTATIVE

(Strike out if an Alternate Representative is not appointed.)

Signature of Alternate Representative	Date Signed (YYYY / MM / DD)
Print Name	

(See Note 9 - additional forms required for this Representation Agreement to be effective)

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

STATUTORY DECLARATON FOR EVIDENCE OF AUTHORITY OF ALTERNATE REPRESENTATIVE

This statutory declaration may be completed by the representative, the alternate representative, or the monitor, as evidence of the authority of the alternate representative to act in place of the representative. This statutory declaration would be completed if one of the circumstances in which the alternate representative is authorized to act in place of the representative occurs to establish the authority of the alternate representative.

CANADA
PROVINCE OF BRITISH COLUMBIA

IN THE MATTER OF the *Representation Agreement Act* re: a Representation Agreement made by

_____ naming _____ as Representative
name of Adult — name of Representative

TO WIT:

I, _____
Name

of _____
Full Address

SOLEMNLY DECLARE THAT:

a. I am the (*strike out the descriptions that do not apply*):
   representative named under the representation agreement
   alternate representative named under the representation agreement
   monitor named under the representation agreement.

b. One of the circumstances referenced in the Representation Agreement in which the alternate representative is authorized to act in place of the representative has occurred, specifically (*describe the specific circumstance resulting in the alternate representative having authority to act*):

_____

_____

AND I make this solemn declaration conscientiously believing it to be true and knowing that it is of the same force and effect as if made under oath.

DECLARED BEFORE ME AT

_____ _____
location — Declarant's Signature

on _____
date

_____
Signature of Commissioner for taking Affidavits
for British Columbia

_____
Commissioner for taking Affidavits for British Columbia
(Apply stamp, or type or legibly print name of commissioner)

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

ON AGREEMENT MADE UNDE
OF THE *REPRESENTATION AGREEMENT ACT*

The notes provided below are for the purpose of providing information only, and do not constitute legal advice.

These notes are prepared for the purposes of this representation agreement form. They should not be considered a complete description of matters to be taken into account in making a representation agreement. A person making a representation agreement, or acting as a representative, alternate representative or monitor, should consult the *Representation Agreement Act* and the Representation Agreement Regulation to ensure that they understand their rights and duties.

NOTE 1: Actions that must be taken to revoke a previous Representation Agreement

To revoke a previous representation agreement, you must also give written notice of the revocation to each representative, each alternate representative, and any monitor named in that representation agreement. Revocation is effective when this notice is given, or on a later date stated in the notice.

NOTE 2: Effect of revocation on a previous section 7 Representation Agreement

If you have previously made a section 7 representation agreement that is still effective, it will be revoked by the revocation provision in this representation agreement.

NOTE 3: Naming a Representative

(a) This form provides for the naming of one representative and one alternate representative. If you wish to name more than one representative to act at the same time, do not use this form.

(b) The *Representation Agreement Act* sets out who may be named as a representative. If an individual is appointed, that individual must be 19 years of age or older, and must not be an individual who provides personal care or health care services to the adult for compensation, or who is an employee of a facility in which the adult resides and through which the adult receives personal care or health care services, unless the individual is a child, parent or spouse of the adult.

(c) A representative must complete the Certificate of Representative or Alternate Representative in Form 1 under the Representation Agreement Regulation.

The information in this note also applies in respect of an alternate representative.

NOTE 4: Statutory declaration for evidence of authority of Alternate Representative

A statutory declaration that may be used is included with this form.

Additional evidence establishing the authority of the alternate representative to act in place of the representative may be required for some purposes.

NOTE 5: What a Representative may and may not be authorized to do under a section 7 Representation Agreement

Under a section 7 representation agreement, a representative may be authorized to help the adult make decisions, or to make decisions on behalf of the adult, about all of the following things:

- the routine management of the adult's financial affairs, as described in the Representation Agreement Regulation;
- obtaining legal services for the adult and instructing counsel to commence proceedings, or to continue, compromise, defend or settle any legal proceedings on the adult's behalf;
- the adult's personal care, and major health care and minor health care, as defined in the *Health Care (Consent) and Care Facility (Admission) Act*.

Under a section 7 representation agreement, a representative may not be authorized to do any of the following:

- to help the adult make decisions, or to make decisions on behalf of the adult, about the adult's financial affairs, other than the routine management of the adult's financial affairs as described in the Representation Agreement Regulation;
- to commence divorce proceedings on the adult's behalf;
- to help make, or to make on the adult's behalf, a decision to refuse health care necessary to preserve life;
- to help the adult make decisions, or to make decisions on behalf of the adult, about the kinds of health care prescribed under section 34 (2) (f) of the *Health Care (Consent) and Care Facility (Admission) Act*;
- despite the objection of the adult, to physically restrain, move or manage the adult, or authorize another person to do these things;

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

Health Act set out in section 11 of t
Agreement Act.

(Please note that this list may not be complete.)

In addition, a representative must not do either of the following:

- consent to the provision of professional services, care or treatment to the adult for the purposes of sterilization for non-therapeutic purposes;
- make or change a will for the adult.

(*Please note that this list may not be complete.)*

NOTE 6: What a Monitor is and whether one is required

(a) A monitor is a person responsible for making reasonable efforts to determine whether a representative is complying with the representative's duties under the *Representation Agreement Act*.

(b) A monitor is required for this representation agreement if the representation agreement authorizes a representative to make, or help make, decisions concerning routine management of the adult's financial affairs, unless the representative is the adult's spouse, the Public Guardian and Trustee, a trust company or a credit union.

(c) A monitor must complete the Certificate of Monitor in Form 2 under the Representation Agreement Regulation.

NOTE 7: Information for witnesses

(a) The following persons may not be a witness:

i. A person named in the representation agreement as a representative or alternate representative;

ii. A spouse, child or parent of a person named in the representation agreement as a representative or alternate representative;

iii. An employee or agent of a person named in the representation agreement as a representative or alternate representative, unless the person named as a representative or an alternate representative is a lawyer, a member in good standing of the Society of Notaries Public of British Columbia, the Public Guardian and Trustee of British Columbia, or a financial institution authorized to carry on trust business under the *Financial Institutions Act*;

iv. A person who is under 19 years of age;

v. A person who does not understand the type of communication used by the adult unless the person receives interpretive assistance to understand that type of communication.

(b) Only one witness is required if the witness is a lawyer or a member in good standing of the Society of Notaries Public of British Columbia.

(c) A witness must complete the Certificate of Witnesses in Form 4 under the Representation Agreement Regulation.

(d) Section 30 of the *Representation Agreement Act* provides for a number of reasons to object to the making and use of a representation agreement. If you believe that you have grounds to make an objection at this time, you must not witness the representation agreement or execute the Certificate of Witnesses, and you may report your objection to the Public Guardian and Trustee of British Columbia.

NOTE 8: When a Representative may exercise authority under this Representation Agreement

Before a person may exercise the authority of a representative under a representation agreement, that person must sign the representation agreement.

NOTE 9: Additional forms required for this Representation Agreement to be effective

The following certificates must be completed, if applicable:

- Form 1 (Certificate of Representative or Alternate Representative);
- Form 2 (Certificate of Monitor), if the Representation Agreement names a Monitor;
- Form 3 (Certificate of Person Signing for the Adult), if a person is signing the Representation Agreement on behalf of the Adult;
- Form 4 (Certificate of Witnesses).

These certificates can be found in the Representation Agreement Regulation.

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

Form 1 - Certificate of Representative or Alternate Representative

To be completed by each representative and alternate representative named in a representation agreement made under section 7 of the *Representation Agreement Act* [sections 5 (4) and 6 (2)].

Part I - Identification of representative or alternate representative

1. This certificate applies to the representation agreement made _____ *[date]*

   by _____ *[name of adult]*.
2. I am named in the representation agreement as representative or alternate representative.
3. My contact information is as follows:

   _____ *[name]*

   _____ *[telephone number]*, of

   _____ *[address]*,

   _____ *[city, province, postal code]*,

   _____ *[date of birth, if not a trust company or credit union]*.

Part 2 - Certifications made by representative or alternate representative

I certify that

(a) I am an adult [does not apply to a trust company or credit union],

(b) I do not provide, for compensation, personal care or health care services to the adult who made the representation agreement, or I do provide the services described in this paragraph, but I am a child, parent or spouse of the adult,

(c) I am not an employee of a facility in which the adult who made the representation agreement resides and through which he or she receives personal care or health care services, or I am an employee described in this paragraph, but I am a child, parent or spouse of the adult,

(d) I am not a witness to the representation agreement,

(e) I have read and understand, and agree to accept, the duties and responsibilities of a representative as set out in section 16 of the *Representation Agreement Act*, and

(f) I have read and understand section 30 of the *Representation Agreement Act* and have no reason to make an objection as described in that section.

_____ _____

signature of representative, alternate representative or authorized signatory of a trust company or credit union *date*

Form 2 - Certificate of Monitor

To be completed by the person named as monitor as set out in section 12 (5) of the *Representation Agreement Act*.

Part I - Identification of monitor

1. This certificate applies to the representation agreement made _____ *[date]*

   by _____ *[name of adult]*.

2. I am named in the representation agreement as monitor.
3. My contact information is as follows:

   _____ *[name]*

   _____ *[telephone number]*, of

   _____ *[address]*,

   _____ *[city, province, postal code]*.

Part 2 - Certifications made by monitor

I certify that

(a) I am an adult,

(b) I have read and understand, and agree to accept, the duties and responsibilities of a monitor as set out in section 20 of the *Representation Agreement Act*, and

(c) I have read and understand section 30 of the *Representation Agreement Act* and have no reason to make an objection as described in that section.

_____ _____

signature of monitor *date*

Form 3 - Certificate of Person Signing for the Adult

To be completed by the person who signs a representation agreement made under section 7 of the *Representation Agreement Act* [section 13 (4) (d)] for the adult making the agreement, if the adult is physically incapable of signing.

Part I - Identification of the person signing on behalf of the adult

1. This certificate applies to the representation agreement made _____ *[date]*

   by _____ *[name of adult]*.
2. I signed the representation agreement on behalf of the adult.
3. My contact information is as follows:

   _____ *[name]*

   _____ *[telephone number]*, of

   _____ *[address]*,

   _____ *[city, province, postal code]*.

Part 2 - Certifications made by the person signing on behalf of the adult

I certify that

(a) I am an adult *[does not apply to a trust company or credit union]*,

(b) the adult who made the representation agreement was present when I signed the representation agreement on his or her behalf, and directed me to sign because he or she was physically incapable of signing,

(c) I understand the type of communication used by the adult who made the representation agreement when he or she directed me to sign the agreement,

(d) I am not named in the representation agreement as a representative or an alternate representative, and

(e) I am not a witness to the representation agreement.

_____ _____

signature of person signing for the adult *date*

Form 4 - Certificate of Witnesses

To be completed by each person witnessing the signing of a representation agreement made under section 7 of the *Representation Agreement Act* [sections 13].

Part I - Identification of, and certifications made by, first witness

1. This certificate applies to the representation agreement made _____ *[date]*

   by _____ *[name of adult]*.

2. I witnessed the signing of the representation agreement by, or on behalf of, the adult.
3. My contact information is as follows:

   _____ *[name]*

   _____ *[telephone number]*, of

   _____ *[address]*,

   _____ *[city, province, postal code]*.

4. I certify that

(a) I am an adult *[does not apply to a trust company or credit union]*,

(b) the adult who made the representation agreement was present when I witnessed the representation agreement,

(c) I understand the type of communication used by the adult who made the representation agreement, or had interpretive assistance to understand that type of communication,

(d) I am not named in the representation agreement as a representative or an alternate representative,

(e) I am not a spouse, child, parent, employee or agent of a person named in the representation agreement as a representative or an alternate representative *[does not apply to an employee or agent of the Public Guardian and Trustee, or a trust company or credit union]*, and

(f) I have read and understand section 30 of the *Representation Agreement Act* and have no reason to make an objection as described in that section.

_____ _____

signature of witness *date*

REPRESENTATION AGREEMENT (SECTION 9)

Print

Made under Section 9 of the *Representation Agreement Act*.

The use of this form is voluntary. Be advised that this form may not be appropriate for use by all persons, as it provides only one option of how a Representation Agreement may be made. In addition, it does not constitute legal advice. For further information, please consult the *Representation Agreement Act* and Representation Agreement Regulation or obtain legal advice.

This form reflects the law at the date of publication. Laws can change over time. Before using this form, you should review the relevant legislation to ensure that there have not been any changes to the legislation or section numbers.

The notes referenced in this Representation Agreement are found at the end of this Agreement and are provided for information only.

1. THIS REPRESENTATION AGREEMENT IS MADE BY ME, THE ADULT:

Full Legal Name of the Adult	Date (YYYY / MM / DD)
Full Address of the Adult	

2. REVOCATION OF PREVIOUS INSTRUMENTS

(See Note 1 – actions that must be taken to revoke a previous Representation Agreement)
(See Note 2 – effect of revocation on previous Representation Agreements)

I revoke all of the following made by me.

- all previous Representation Agreements granting authority under section 7 of the *Representation Agreement Act*;
- all previous Representation Agreements granting authority under section 9 of the *Representation Agreement Act*.

3. REPRESENTATIVE

(See Note 3 –who may be named as Representative)

I name the following person to be my Representative:

Full Legal Name of Representative
Full Address of Representative

4. ALTERNATE REPRESENTATIVE (OPTIONAL)

(See Note 3 – who may be named as Representative)
(Strike out this provision if you do not want to appoint an Alternate Representative.)

If my Representative

- dies,
- resigns in accordance with the *Representation Agreement Act*,
- is my spouse, as defined in the *Representation Agreement Act*, at the time that I make this Representation Agreement, and our marriage or marriage-like relationship subsequently terminates as set out in the *Representation Agreement Act*, or
- becomes incapable,

then I name the following person to be my Alternate Representative:

Full Legal Name of Alternate Representative
Full Address of Alternate Representative

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

5. EVIDENCE OF AUTHORITY OF ALTERNATE REPRESENTATIVE

(See Note 4 – statutory declaration for evidence of authority of Alternate Representative)
(Strike out this provision if you are not appointing an Alternate Representative.)

A statutory declaration made by me, my Representative, or my Alternate Representative (if one is named), declaring that one of the circumstances referenced in section 4 of this Representation Agreement has occurred, and specifying that circumstance, is sufficient evidence of the authority of my Alternate Representative to act in place of my Representative.

6. AUTHORITY OF REPRESENTATIVE

(See Note 5 - what a Representative may and may not do)

Pursuant to section 9 (1) (a) of the *Representation Agreement Act*, I authorize my Representative to do anything that the Representative considers necessary in relation to my personal care and health care.

7. INSTRUCTIONS OR WISHES (OPTIONAL)

(See Note 6 - consultation with a health care provider)

The following are my instructions or wishes with respect to decisions that will be made within the areas of authority given to my Representative under this Representation Agreement:

8. EFFECTIVE DATE

This Representation Agreement becomes effective on the date it is executed.

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

9. SIGNATURES

ADULT AND WITNESS SIGNATURES

ADULT'S SIGNATURE

- The Adult must sign and date in the presence of both Witnesses.

Signature of Adult	Date Signed (YYYY / MM / DD)
Print Name	

WITNESSES TO ADULT'S SIGNATURE

(See Note 7 – information for witnesses)

WITNESS NO. 1

- Witness No. 1 must sign in the presence of the Adult and Witness No. 2.

Signature of Witness No. 1	Date Signed (YYYY / MM / DD)
Print Name	
Address	
If witness is a lawyer or member of the Society of Notaries Public of British Columbia, check relevant box below: ☐ lawyer ☐ member of the Society of Notaries Public of British Columbia	

WITNESS NO. 2

- Not required if Witness No. 1 is a lawyer or member in good standing of the Society of Notaries Public of British Columbia.
- Witness No. 2 must sign in the presence of the Adult and Witness No. 1.

Signature of Witness No. 2	Date Signed (YYYY / MM / DD)
Print Name	
Address	

REPRESENTATIVES' SIGNATURES

(See Note 8 - when a Representative may exercise authority under this Representation Agreement)

REPRESENTATIVE

Signature of Representative	Date Signed (YYYY / MM / DD)
Print Name	

ALTERNATE REPRESENTATIVE

(Strike out if an Alternate Representative is not appointed.)

Signature of Alternate Representative	Date Signed (YYYY / MM / DD)
Print Name	

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

STATUTORY DECLARATON FOR EVIDENCE OF AUTHORITY OF ALTERNATE REPRESENTATIVE

This statutory declaration may be completed by the adult, the representative, or the alternate representative, as evidence of the authority of the alternate representative to act in place of the representative. This statutory declaration would be completed if one of the circumstances in which the alternate representative is authorized to act in place of the representative occurs to establish the authority of the alternate representative.

CANADA
PROVINCE OF BRITISH COLUMBIA

IN THE MATTER OF the *Representation Agreement Act* re: a Representation Agreement made by

_____ naming _____ as Representative
name of Adult — name of Representative

TO WIT:

I, _____
Name

of _____
Full Address

SOLEMNLY DECLARE THAT:

a. I am the (*strike out the descriptions that do not apply*):
   adult who made the representation agreement
   representative named under the representation agreement
   alternate representative named under the representation agreement.

b. One of the circumstances referenced in the Representation Agreement in which the alternate representative is authorized to act in place of the representative has occurred, specifically (*describe the specific circumstance resulting in the alternate representative having authority to act*):

_____

_____

AND I make this solemn declaration conscientiously believing it to be true and knowing that it is of the same force and effect as if made under oath.

DECLARED BEFORE ME AT

_____ _____
location — Declarant's Signature

on _____
date

_____
Signature of Commissioner for taking Affidavits
for British Columbia

_____
Commissioner for taking Affidavits for British Columbia
(Apply stamp, or type or legibly print name of commissioner)

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

ON AGREEMENT MADE UNDE
OF THE *REPRESENTATION AGREEMENT ACT*

The notes provided below are for the purpose of providing information only, and do not constitute legal advice.

These notes are prepared for the purposes of this representation agreement form. They should not be considered a complete description of matters to be taken into account in making a representation agreement. A person making a representation agreement, or acting as a representative or alternate representative, should consult the *Representation Agreement Act* and the Representation Agreement Regulation to ensure that they understand their rights and duties.

NOTE 1: Actions that must be taken to revoke a previous Representation Agreement

To revoke a previous representation agreement, you must also give written notice of the revocation to each representative, each alternate representative, and any monitor named in that representation agreement. Revocation is effective when this notice is given, or on a later date stated in the notice.

NOTE 2: Effect of revocation on previous Representation Agreements

The revocation provision in this representation agreement will do all of the following:

- if you have previously made a section 7 representation agreement that is still effective, it will be revoked;
- if you have previously made a section 9 representation agreement that is still effective, it will be revoked.

NOTE 3: Who may be named as Representative

(a) This form provides for the naming of one representative and one alternate representative. If you wish to name more than one representative to act at the same time, do not use this form.

(b) The *Representation Agreement Act* sets out who may be named as a representative. If an individual is appointed, that individual must be 19 years of age or older, and must not be an individual who provides personal care or health care services to the adult for compensation, or who is an employee of a facility in which the adult resides and through which the adult receives personal care or health care services, unless the individual is a child, parent or spouse of the adult.

The information in this note also applies in respect of an alternate representative.

NOTE 4: Statutory declaration for evidence of authority of Alternate Representative

A statutory declaration that may be used is included with this form.

Additional evidence establishing the authority of the alternate representative to act in place of the representative may be required for some purposes.

NOTE 5: What a Representative may and may not do

The authority of a representative appointed under this representation agreement includes the power to give or refuse consent to health care necessary to preserve life.

A representative appointed under this representation agreement must not do any of the following:

- give or refuse consent on the adult's behalf to any type of health care prescribed under section 34 (2) (f) of the *Health Care (Consent) and Care Facility (Admission) Act;*
- make arrangements for the temporary care and education of the adult's minor children, or any other persons who are cared for or supported by the adult;
- interfere with the adult's religious practices.

(Please note this list may not be complete.)

If you want your representative to be authorized to do the things on the above list, you should obtain legal advice.

In addition, under the *Representation Agreement Act*, a representative:

- may not be authorized to refuse consent to those matters in relation to the *Mental Health Act* set out in section 11 of the *Representation Agreement Act*;
- must not consent to the provision of professional services, care or treatment to the adult for the purposes of sterilization for non-therapeutic purposes;
- must not make or change a will for the adult.

(Please note that this list may not be complete.)

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

If you choose to include instructions or wishes in your representation agreement about your health care, you may wish to discuss with a health care provider the options and the possible implications of your choices.

NOTE 7: Information for witnesses

(a) The following persons may not be a witness:

i. A person named in the representation agreement as a representative or alternate representative;

ii. A spouse, child or parent of a person named in the representation agreement as a representative or alternate representative;

iii. An employee or agent of a person named in the representation agreement as a representative or alternate representative, unless the person named as a representative or alternate representative is a lawyer, a member in good standing of the Society of Notaries Public of British Columbia, or the Public Guardian and Trustee of British Columbia;

iv. A person who is under 19 years of age;

v. A person who does not understand the type of communication used by the adult unless the person receives interpretive assistance to understand that type of communication.

(b) Only one witness is required if the witness is a lawyer or a member in good standing of the Society of Notaries Public of British Columbia.

(c) Section 30 of the *Representation Agreement Act* provides for a number of reasons to object to the making and use of a representation agreement. If you believe that you have grounds to make an objection at this time, you should not witness the representation agreement and you may report your objection to the Public Guardian and Trustee of British Columbia.

NOTE 8: When a Representative may exercise authority under this Representation Agreement

Before a person may exercise the authority of a representative under a representation agreement, that person must sign the representation agreement.

PUBLISHED BY THE ATTORNEY GENERAL OF BRITISH COLUMBIA, SEPTEMBER 2011

ADVANCE DIRECTIVE

Made under the *Health Care (Consent) and Care Facility (Admission) Act*

The use of this form is voluntary. Before completing this Advance Directive, it is advisable to obtain legal advice and the advice of a health care provider about the possible implications of this Advance Directive, and your choices about the types of health care for which you might give or refuse consent under this Advance Directive.

The notes referenced in this Advance Directive are found at the end of this Advance Directive and are provided for informational purposes only. (See Note 1 – limitations on the effect of this Advance Directive.)

1. THIS IS THE ADVANCE DIRECTIVE OF THE "ADULT":

Full Legal Name of the Adult	Date (YYYY / MM / DD)
Full Address of the Adult	
Date of Birth (YYYY / MM / DD)	(OPTIONAL) Personal Health (CareCard) Number

2. REVOCATION OF PREVIOUS ADVANCE DIRECTIVES:

I revoke all previous Advance Directives made by me.

3. CONSENT TO HEALTH CARE AND REFUSAL OF CONSENT TO HEALTH CARE:

If I need health care and I am not capable of giving or refusing consent to the health care at the time the health care is required, **I give the following instructions**:

[Note: If a health care decision is required while you are incapable but the type of health care is not addressed in this Advance Directive, the decision will be made by a substitute decision maker.]

I consent to the following health care:

I refuse to consent to the following health care:

I know that as a result of making this Advance Directive

a. I will not be provided with any health care for which I refuse consent in this Advance Directive, and

b. No one will be chosen to make decisions on my behalf in respect of any health care matters for which I give or refuse consent in this Advance Directive.

(See Note 1 – limitations on the effect of this Advance Directive)

5. SIGNATURES

ADULT'S SIGNATURE

- The Adult must sign and date in the presence of both Witnesses.

	Date Signed (YYYY / MM / DD)

WITNESSES TO ADULT'S SIGNATURE - SEE NOTE 2, INFORMATION FOR WITNESSES

WITNESS NO. 1

- Witness No. 1 must sign in the presence of the Adult and Witness No. 2.

Signature of Witness No. 1	Date Signed (YYYY / MM / DD)
Print Name	
Address	

WITNESS NO. 2

- Not required if Witness No. 1 is a lawyer or notary public.
- Witness No. 2 must sign in the presence of the Adult and Witness No. 1.

Signature of Witness No. 2	Date Signed (YYYY / MM / DD)
Print Name	
Address	

NOTES RESPECTING ADVANCE DIRECTIVES

The notes provided below are for the purposes of providing information only.

These notes should NOT be considered complete: a person making an Advance Directive should consult the *Health Care (Consent) and Care Facility (Admission) Act* to ensure that they understand their rights and duties.

NOTE 1: LIMITATIONS ON THE EFFECT OF THIS ADVANCE DIRECTIVE

Note that the effect of this Advance Directive and the giving and refusing of consent under it is subject to the limitations set out in sections 19.2 (2), 19.3 (1) and 19.8 of the *Health Care (Consent) and Care Facility (Admission) Act*.

NOTE 2: INFORMATION FOR WITNESSES

(a) The following persons may not be a witness:

i. A person who provides personal care, health care or financial services to the adult for compensation, other than a lawyer or notary public;

ii. A spouse, child, parent, employee or agent of a person described in paragraph (a);

iii. A person who is under 19 years of age;

iv. A person who does not understand the type of communication used by the Adult, unless the person receives interpretive assistance to understand that type of communication.

(b) Only one witness is required if the witness is a lawyer or notary public.

(c) You should not witness the Advance Directive if you have reason to believe that

i. the Adult is incapable of making, changing or revoking an Advance Directive, or

ii. fraud, undue pressure or some other form of abuse or neglect was used to induce the Adult to make the Advance Directive, or to change or revoke a previous Advance Directive.

Advance Care Planning

For more information about advance care planning, visit:
SeniorsBC - www.seniorsbc.ca
HealthLink BC (www.healthlinkbc.ca)and search for advance care planning, or call 8-1-1.

Your local health authority:
Fraser Health - www.fraserhealth.ca/your_care/advance_care_planning
Interior Health - www.interiorhealth.ca/YourCare/EndOfLife/AdvanceCarePlanning
Northern Health - www.northernhealth.ca/YourHealth/AdvanceCarePlanning.aspx
Vancouver Coastal Health - www.vch.ca/your_health/health_topics/advance_care_planning
Vancouver Island Health Authority - www.viha.ca/advance_care_planning

Legislation

For information on B.C.'s incapacity planning legislation, visit the Ministry of Attorney General at:
www.ag.gov.bc.ca/incapacity-planning

Personal Planning

The Public Guardian and Trustee - www.trustee.bc.ca/services/adult/personal_planning_tools.html
Nidus Personal Planning Resource Centre - www.nidus.ca

Health Care Needs

If you need a family doctor, the College of Physicians and Surgeons of British Columbia provides a directory of physicians accepting new patients at: www.cpsbc.ca/node/216

Legal Needs

If you need a lawyer, the Canadian Bar Association British Columbia branch operates the Lawyer Referral Service. For details, visit: www.cba.org/BC/Initiatives/main/lawyer_referral.aspx

My full name is _____

In case of emergency, call:

_____ (name) _____ (phone)

My health care provider is _____

I have an advance care plan ❑
- ❑ with a representation agreement [❑ sec 7 ❑ sec 9]
- ❑ with an advance directive

I am an organ donor ❑

My important papers are located _____

Return to My Voice Table of Contents

Return to Page 1

Print
Return to Page 1











Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.

Institute *for* Healthcare Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

Return to Page 1

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

NAME

DATE

HOW TO USE THE STARTER KIT

This Starter Kit doesn't answer every question, but it will help you get your thoughts together, and then have the conversation with your loved ones.

You can use it whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Take your time. This kit is not meant to be completed in one sitting. It's meant to be completed as you need it, throughout many conversations.

TABLE OF CONTENTS

Why talking matters 2

Step 1: Get Ready 3

Step 2: Get Set 4

Step 3: Go 7

Step 4: Keep Going 10

Return to Page 1

Why talking matters

Sharing your wishes for end-of-life care can bring you closer to the people you love. It's critically important. And you can do it. **Consider the facts:**

90% of people say that talking with their loved ones about end-of-life care is important.

27% have actually done so.

Source: The Conversation Project National Survey (2013)

60% of people say that making sure their family is not burdened by tough decisions is extremely important.

56% have not communicated their end-of life wishes.

Source: Survey of Californians by the California HealthCare Foundation (2012)

80% of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.

7% report having had this conversation with their doctor.

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it's important to put their wishes in writing.

23% have actually done it.

Source: Survey of Californians by the California HealthCare Foundation (2012)

One conversation can make all the difference.

Return to Page 1

Step 1 Get Ready

You will have many questions as you get ready for the conversation. **Here are two to help you get started:**

? **What do you need to think about or do before you feel ready to have the conversation?**

? **Do you have any particular concerns that you want to be sure to talk about?** (For example, making sure finances are in order; or making sure a particular family member is taken care of.)

REMEMBER:

- You don't need to have the conversation just yet. It's okay to just start thinking about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend.
- You might consider having a practice conversation with a friend.
- Having the conversation may reveal that you and your loved ones disagree. That's okay. It's important to simply know this, and to continue talking about it now—not during a medical crisis.
- Having the conversation isn't just a one-time thing. It's the first in a series of conversations over time.

Return to Page 1

Step 2 Get Set

What's most important to you as you think about how you want to live at the end of your life? What do you value most? **Thinking about this will help you get ready to have the conversation.**

? **Now finish this sentence: What matters to me at the end of life is...**
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

Sharing your "what matters to me" statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

WHERE I STAND SCALES

Use the scales below to figure out how you want your end-of-life care to be. Select the number that best represents your feelings on the given scenario.

As a patient, I'd like to know...

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

Only the basics about my condition and my treatment

All the details about my condition and my treatment

As doctors treat me, I would like...

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

My doctors to do what they think is best

To have a say in every decision

Return to Page 1

If I had a terminal illness, I would prefer to...

◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
Not know how quickly it is progressing				Know my doctors best estimation for how long I have to live

? **Look at your answers.**
What kind of role do you want to have in the decision-making process?

How long do you want to receive medical care?

◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
Indefinitely, no matter how uncomfortable treatments are				Quality of life is more important to me than quantity

What are your concerns about treatment?

◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
I'm worried that I won't get enough care				I'm worried that I'll get overly aggressive care

What are your preferences about where you want to be?

◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
I wouldn't mind spending my last days in a health care facility				I want to spend my last days at home

? **Look at your answers.**
What do you notice about the kind of care you want to receive?

Return to Page 1

How involved do you want your loved ones to be?

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable

I want my loved ones to do what brings them peace, even if it goes against what I've said

When it comes to your privacy...

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

When the time comes, I want to be alone

I want to be surrounded by my loved ones

When it comes to sharing information...

○ 1 ○ 2 ○ 3 ○ 4 ○ 5

I don't want my loved ones to know everything about my health

I am comfortable with those close to me knowing everything about my health

? **Look at your answers.**
What role do you want your loved ones to play? Do you think that your loved ones know what you want, or do you think they have no idea?

? **What do you feel are the three most important things that you want your friends, family, and/or doctors to understand about your wishes and preferences for end-of-life care?**

1.

2.

3.

Return to Page 1

Step 3 Go

When you're ready to have the conversation, think about the basics.

MARK ALL THAT APPLY:

? WHO do you want to talk to?

- ☐ Mom
- ☐ Dad
- ☐ Child/Children
- ☐ Partner/Spouse
- ☐ Sister/Brother
- ☐ Faith leader (Minister, Priest, Rabbi, Imam, etc.)
- ☐ Friend
- ☐ Doctor
- ☐ Caregiver
- ☐ Other:

? WHEN would be a good time to talk?

- ☐ The next holiday
- ☐ Before my child goes to college
- ☐ Before my next trip
- ☐ Before I get sick again
- ☐ Before the baby arrives
- ☐ The next time I visit my parents/ adult children
- ☐ At the next family gathering
- ☐ Other:

? WHERE would you feel comfortable talking?

- ☐ At the kitchen table
- ☐ At a favorite restaurant
- ☐ In the car
- ☐ On a walk
- ☐ Sitting in a park
- ☐ At my place of worship
- ☐ Other:

? WHAT do you want to be sure to say?
If you wrote down your three most important things at the end of Step 2, you can use those here.

Return to Page 1

How to start

Here are some ways you could break the ice:

"I need your help with something."

"Remember how someone in the family died—was it a 'good' death or a 'hard' death? How will yours be different?"

"I was thinking about what happened to _____, and it made me realize..."

"Even though I'm okay right now, I'm worried that _____, and I want to be prepared."

"I need to think about the future. Will you help me?"

"I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."

What to talk about:

- ☐ When you think about the last phase of your life, what's most important to you? How would you like this phase to be?
- ☐ Do you have any particular concerns about your health? About the last phase of your life?
- ☐ What affairs do you need to get in order, or talk to your loved ones about? *(Personal finances, property, relationships)*
- ☐ Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you're not able to? *(This person is your health care proxy.)*
- ☐ Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?
- ☐ Are there any disagreements or family tensions that you're concerned about?
- ☐ Are there important milestones you'd like to be there for, if possible? *(The birth of your grandchild, your 80th birthday.)*

Return to Page 1

- ☐ Where do you want (or not want) to receive care? *(Home, nursing facility, hospital)*
- ☐ Are there kinds of treatment you would want (or not want)? *(Resuscitation if your heart stops, breathing machine, feeding tube)*
- ☐ When would it be okay to shift from a focus on curative care to a focus on comfort care alone?

This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your doctor or nurse if you'd like them to suggest more questions to talk about.

REMEMBER:

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances change.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don't have to cover everyone or everything right now.

Now, just go for it! Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.

Return to Page 1

Step 4 Keep Going *in BC*

This booklet is developed in the United States by the Conversation Project. The information provided in **Step 4** does not apply to British Columbia. The correct information for British Columbia is provided below:

- **A Will**
  Appoints an executor to handle your estate after you've passed away. You can do this independently; however, it is advisable to do this with a lawyer. A Will cannot be made if you are not mentally competent.

- **Enduring Power of Attorney**
  Appoints a power of attorney to make legal and financial decisions on your behalf should you become physically or mentally incapable of making these decisions. You must do this with a lawyer or notary public.

- **Representation Agreement**
  Appoints a representative to assist you or act on your behalf to make health and personal care decisions according to your wishes, values and beliefs. You can do this independently; however, it is advisable to do this with a lawyer.

- **Advanced Directive**
  A legal document providing specific instructions about healthcare treatments. This document can supersede a representative's decision. It is also advisable to do an Advanced Directive with a lawyer.

A "Living Will" is not a legal document in British Columbia. A Representative Agreement or an Advance Directive are required to have your medical wishes honoured.

You can find more information about wills and estate planning from British Columbia Legal Services Society: www.mylawbc.com.
You can find more information about the other documents at www.nidus.ca. (Nidus is a public resource for British Columbians with information on personal planning tools).

Updated by the Powell River Division of Family Practice

Powell River
Division of Family Practice
A GPSC initiative

divisionsbc.ca/powellriver

Return to Page 1

? **Is there something you need to clarify that you feel was misunderstood or misinterpreted?**

? **Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who tend to disagree)?**

? **How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?**

? **What do you want to make sure to ask or talk about next time?**

We hope you will share this Starter Kit with others.

You have helped us get one conversation closer to our goal: that everyone's end-of-life wishes are expressed and respected. Please send us your feedback or request additional information at conversationproject@ihi.org.

Return to Page 1

the gold standards framework

4th Edition
October 2011

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

RCGP Royal College of General Practitioners

Why is it important to identify people nearing the end of life?

'Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care'

(GSF National Primary Care Snapshot Audit 2010)

About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-co-ordinated, high quality care.

This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such clarifying their particular needs, offering advance care planning discussions prevention of crises admissions and pro-active support to ensure they 'live well until they die'.

Predicting needs rather than exact prognostication. This is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

Definition of End of Life Care
General Medical Council, UK 2010

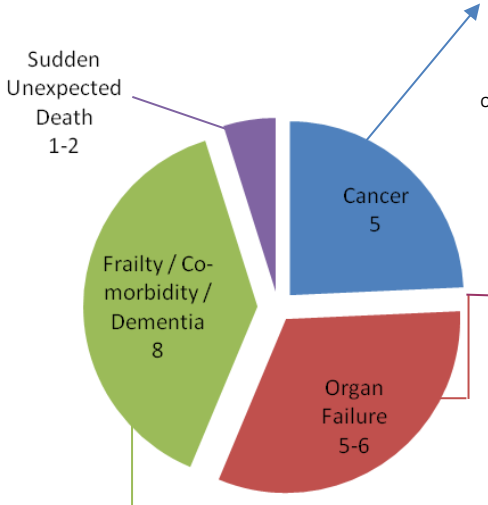
People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

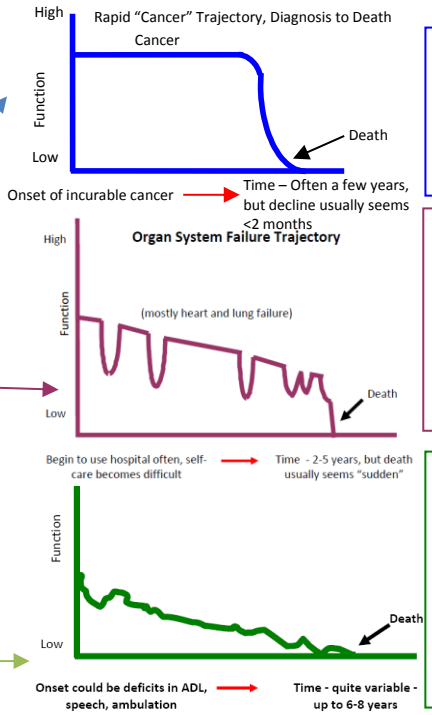
- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Three triggers that suggest that patients are nearing the end of life are:

1. **The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?**
2. **General indicators of decline - deterioration, increasing need or choice for no further active care.**
3. **Specific clinical indicators related to certain conditions.**

Average GP's workload – average 20 deaths/GP/year approx. proportions





Typical Case Histories

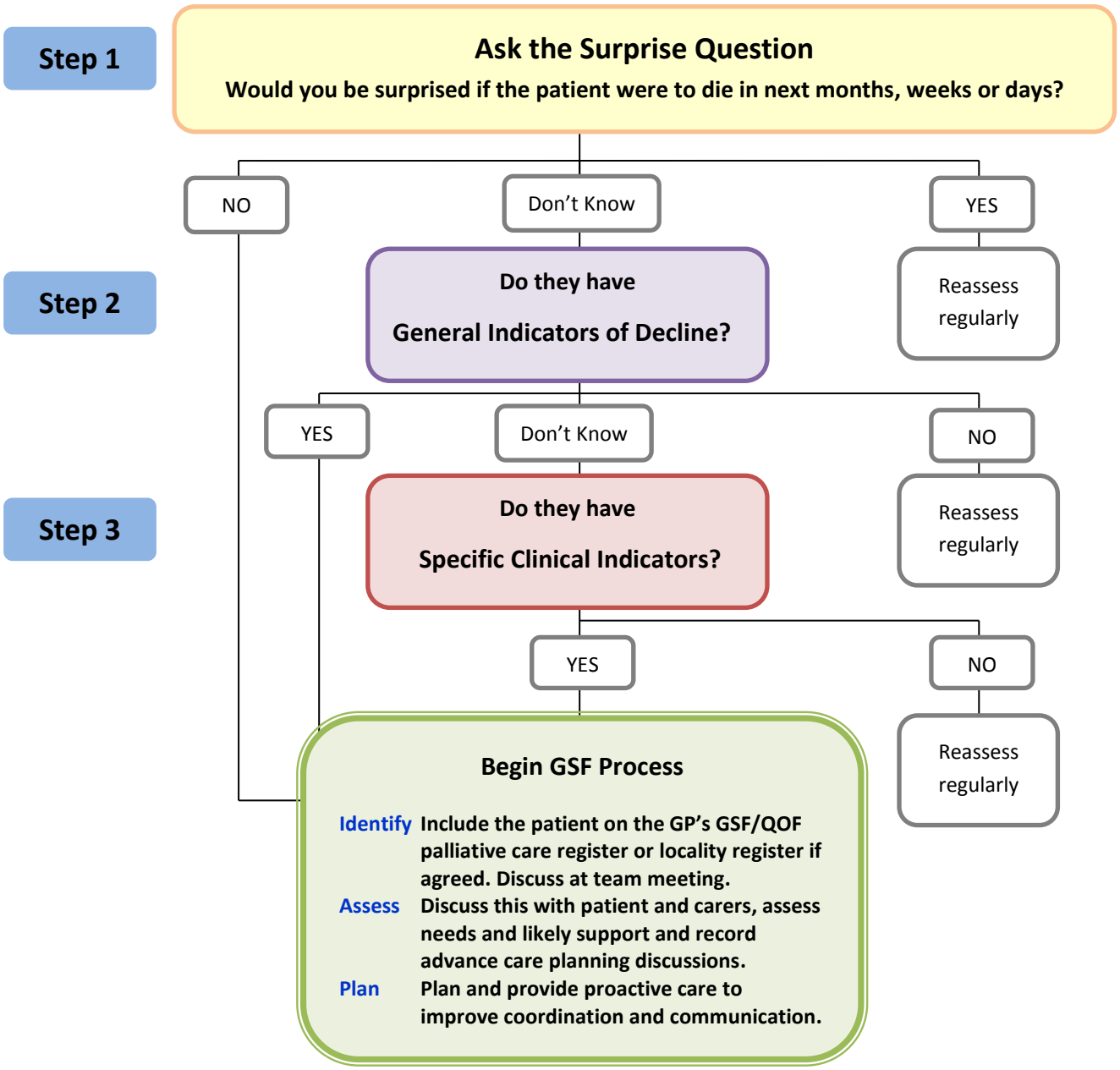
1) Mrs A - A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline

2) Mr B – An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and coping alone in future. Decreasing recovery and likely erratic decline

3) Mrs C – A 91 year old lady with COPD, heart failure, osteoarthritis, and increasing signs of dementia, who lives in a care home. Following a fall, she grows less active, eats less, becomes easily confused and has repeated infections. She appears to be 'skating on thin ice'. Difficult to predict but likely slow decline

Return to Page 1

Summary of suggested three steps for earlier identification

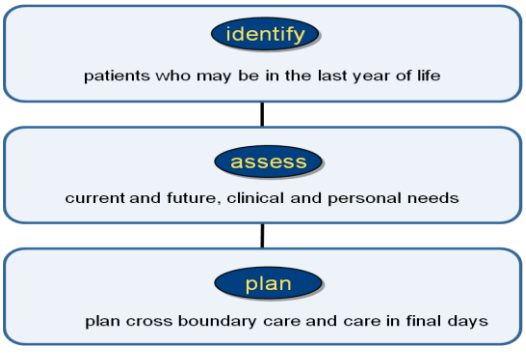


How to use this guidance – what next?

GSF Needs Based Coding

This guidance aims to clarify the triggers that help to identify patients who might be eligible for inclusion on the register (supportive/palliative care/ GSF/ locality registers). Once identified and included on the register, such patients may be able to receive additional proactive support, leading to better co-ordinated care that also reflects people's preferences. This is in line with thinking on shared decision-making processes and the importance of integrating advance care planning discussions into delivery of care. It is based on consideration of people's needs rather than exact timescales, acknowledging that people need different things at different times. Earlier recognition of possible illness trajectories means their needs can be better anticipated and addressed. Specific tasks for each stage are part of the GSF Programmes in different settings, to enable better proactive coordinated care.

GSF 3 Steps Process



Return to Page 1

Step 1 The Surprise Question

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

Step 2 General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

Functional Assessments

Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc .

PULSE 'screening' assessment - P (physical condition); U (upper limb function);
L (lower limb function); S (sensory);
E (environment).

Karnofksy Performance Status Score
0-100 ADL scale .

WHO/ECOG Performance Status
0-5 scale of activity.

Step 3 Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

a) Cancer – rapid or predictable decline

Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PiPS (UK validated Prognosis in Palliative care Study). PPI, PPS etc. 'Prognosis tools can help but should not be applied blindly'
- 'The single most important predictive factor in cancer is performance status and functional ability' - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less.

b) Organ Failure – erratic decline

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level of confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease

At least two of the indicators below:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Return to Page 1

Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

General Neurological Diseases

- Progressive deterioration in physical and/ or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia. Plus the following:

Motor Neurone Disease

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below.

Multiple Sclerosis

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia.

c) Frailty / Dementia – gradual decline

Frailty

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofksy
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression.

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3.

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

Return to Page 1

Use of needs based coding

Prognostication or prediction of need.

Rainy day thinking.

"Hope for the best but prepare for the worst."

Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators. Most people tend to give undue weight to prognosis and too little to the importance of planning for possible need, especially for those with non-cancer illnesses, frailty and co-morbidities. In order to identify more accurately those patients who need additional pro-active supportive care, the focus should be on a pragmatic, even instinctive, prediction of the rate and course of decline. Some specific tools can help to predict accurately the time remaining for cancer patients but they should be used with caution (BMJ .2011; 343:d5171)

We suggest a move towards earlier consideration and more 'rainy day thinking' – bringing an umbrella just in case it rains. This instinctive, anticipatory and 'insurance-type' thinking relates more to meeting likely needs and planning ahead, rather than focusing on trying to predict likely timescales, and should ensure appropriate support and care can be mobilised.

If you can anticipate possible deterioration, then you can begin discussions about preferences and needs at an earlier stage. The aim of such advance care planning discussions is to establish patients' sometimes unvoiced concerns, needs and preferences, enabling more people to live out the final stage of life as they choose (see ACP Guidance on GSF/ EOLC web-sites). This also means you can introduce practical measures to prevent crises and make referrals for extra help or advice.

Needs Based Coding - the right care at the right time

Patients have differing requirements at varying stages of their illness. The use of needs-based or colour coding can be very helpful in prioritising need. Some clinicians in care homes, GP practices and hospitals use this system to identify their patients' stage of decline and so predict at an earlier stage their future needs. Although only a rough guide, this helps us focus on giving the right care at the right time, with regular reviews built in to trigger actions at each stage. As a result a needs/support care plan can be developed for each individual.

Needs Based Coding and Needs Support Matrices

Identifying the stage of illness and anticipating needs and support– to deliver the right care at the right time for the right patient

- **A – All – stable from diagnosis** — **years**
- **B – Unstable, advanced disease** — **months**
- **C – Deteriorating, exacerbations** — **weeks**
- **D – Last days of life pathway** — **days**

For further details of use of Needs / Support Coding and Matrices as part of the GSF Programmes contact the GSF Centre.

Long term conditions. There is a strong correlation between care for patients with long-term conditions and those with advanced disease nearing the end of life. This is especially true for patients with organ failure (heart failure, COPD). Close collaboration with case managers can reduce unplanned admissions and support good end of life care.

Use of this guidance by different teams

Primary care teams. Identifying patients, the first step of GSF, is key to developing a Palliative Care Register, which forms part of the QOF palliative care points in the GMS contract.

The National Primary Care Snapshot Audit (2010) in England demonstrated 3 key findings:

- Only about **25%** of patients who died were included on the GP's Palliative Care/ GSF register
- Only **25%** of these had non-cancer conditions
- Most importantly, those patients identified early and included on the register received **better quality coordinated** care

Therefore this affirms the need for earlier recognition and identification of people nearing the end of life where possible, i.e. the 1% of the population who die each year, greater representation of patients with non-cancer, organ failure, and those with frailty and dementia is recommended, including those from care homes.

Two helpful questions for practice teams to ask:

1. **What is your register ratio?** The number of patients on your palliative care register over the number who died in your practice (using the 1% rule as an approximation e.g. 5000 population = about 50 deaths/ year).
2. **What is your non-cancer/cancer ratio on register?** What percentage of patients on the register has cancer or non-cancer conditions as their main cause of death?

For more details on the QOF points and guidance on Next Stage GSF in Primary care, see the GSF website.

Care homes. Use of the surprise question and this guidance has been found to help identify residents who are most in need in care homes. This can help focus care and trigger key pro-active support, thereby leading to reduced hospital deaths (e.g. halving of death rate in care homes using GSF in Care Homes Programme).

Acute hospital teams. About 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there. Improved early identification of people in the final year of life helps reduce hospitalisation and accessing supportive and palliative care services. It is extremely helpful if hospital teams notify GPs that a particular patient has advanced disease and might be included on their register.

Specialist teams. Specialist palliative care teams play a vital role especially with cancer patients, but there is a need for collaboration with other specialist teams for non-cancer patients to provide optimal care. These include those with dementia, care of the elderly, heart failure, etc. and this guidance may help clarify referrals.

Commissioners/managers. This guidance could be used as part of an end of life care strategic plan, with improved provision of services for all patients nearing the end of life and introduction of a locality register.

Return to Page 1

"It should be possible therefore to predict the majority of deaths, however, this is difficult and errors occur 30 per cent of the time… However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need. **Identifying** patients in need of palliative care, **assessing** their needs and preferences and proactively **planning** their care, are the key steps in the provision of high quality care at the end of life in general practice."

(Quality and Outcomes Framework (QOF Guidance) 2011/12 Guidance)

'It is recommended that people approaching the end of life are identified in a timely way.'
(Draft Recommendation NICE Guidance in End of Life Care 2001)

This is not attempting to answer the question that doctors often hear - 'how long have I got?' Rather, it responds to the underlying sometimes unspoken questions from people facing a new reality 'If I haven't got long, then what should I do and how can you help?'
(Thomas K GSF Centre 2008)

"For many people suffering from a chronic illness, a point is reached where it is clear that the person will die from their condition. Despite this, for many conditions it may be difficult, if not impossible and potentially unhelpful, to estimate prognosis accurately. The Prognostic Indicator Guidance developed as part of the Gold Standards Framework (GSF) provides useful prompts or triggers to a healthcare professional that discussions about the end of life should be initiated, if this has not already happened". (DH End of Life care Strategy 2008 England)

Identification of people with a life-limiting illness when they are starting to need a change in their goals of care contributes to end of life care planning and can aid communication with patients and families. It depends on clinical judgement and weighing up a complex mix of pathology, clinical findings, therapeutic response, co-morbidities, psychosocial factors, and rate of decline. (Glare P J Palliat Med 2008)

"Using the GSF 'PIG' has helped us to identify these patients earlier than we previously did, especially those with non-cancer, thereby giving them earlier support as they face the end of their lives, leading to fewer crises and hospital admissions." (GP using Next Stage GSF Training Programme 'Going for Gold')

Development of this guidance paper. This guidance was originally commissioned from the GSF Centre in June 2006 to support GPs include appropriate patients on their QOF Palliative Care Registers i.e. those considered to be in the final 12 months of life. It is regularly revised following extensive consultation with clinical and disease specialist groups, palliative care specialists and GPs in the Royal College of General Practitioners. Particular thanks go to the NHS End of Life Care Programme and University of Edinburgh team for their help. Since publication, this Guidance has been widely used by clinicians in many sectors in the UK and internationally. A list of detailed references is available on request. This is one of several tools available to support improvements in End of Life Care, and further details on best use, IT support and further developments can be obtained from the GSF Centre.

Resources and Further Reading :

National Gold Standards Framework Centre for End od Life Care- Primary care, care homes and other areas www.goldstandardsframework.org.uk
National Primary care Snapshot Audit (2009/2010) DH report + Next Stage GSF Primary Care Training www.goldstandardsframework.org.uk/GSFInPrimary+Care
NHS End of life care Programme www.endoflifecareforadults.nhs.uk
NHS Department of Health. End of Life Care Strategy (2008) P51, 3.22 http://www.endoflifecareforadults.nhs.uk/strategy/strategy
GMC End of Life Care www.gmc-uk.org/static/documents/content/End_of_life.pdf3
QOF Palliative Care - www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract_2011_12_FL%2013042011.pdf
NICE Draft Quality standards in End of Life Care (for consultation- due Nov 2011) www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp
National Audit Office End of Life care Report Nov 08 www.nao.org.uk/publications/0708/end_of_life_care.aspx
British Geriatrics Society. www.bgs.org.uk/index.php?option=com_content...id
The'Surprise question': Lynn J 2005 Altarum Institute Center for Elder Care and Advanced Illness www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf
Dying Matters- and the QIPP Find the 1% campaign –www.dyingmatters .org.uk or National Council for Palliative Care www.ncpc.org.uk
Liverpool Care Pathway for the Dying Patient. http://www.mcpcil.org.uk/liverpool-care-pathway/
QIPP Department of Health www.endoflifecareforadults.nhs.uk/strategy/policy/quality-innovation-productivity-prevention
Frameworks for Implementation (2010) from the End of Life Care Programmes - www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework, www.kidneycare.nhs.uk/Library/EndofLifeCareFINAL.pdf, www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia, www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework
Renal advisory group of the NSF, British Renal Society, and British Transplant Society. www.britishrenal.org
Barthel Score: Barthel's index of activities of daily living (BAI), www.patient.co.uk/showdoc/40001654/
Glare P (2011). Predicting and communicating prognosis in palliative care. *BMJ*;343:d5171
Glare P, Sinclair CT (2008). Palliative medicine review: prognostication. *J Palliat Med*;11;84-103
Gwilliam B, Keeley V, Todd C, Gittins M, Roberts C, Kelly L (2011) Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ*;343:d4920
McDaid P (2011) Quick Guide to Identifying Patients , Islington PCT, (personal communication)
Quinn TJ, McArthur K, Ellis G, Stott DJ (2011).Functional assessment in older people. *BMJ* ;343:d4681
Quinn TJ, Langhorne P, Stott DJ (2011). Barthel index for stroke trials: development, properties and application. *Stroke*; 42:1146-51
SPICT Guidance University of Edinburgh (2010). Supportive and Palliative Care Indicators tool (SPCIT) www.palliativecareguidelines.scot.nhs.uk/careplanning/
SPOTLIGHT: Palliative care beyond cancer: Recognising and managing key transitions in end of life care: Boyd K , Murray S BMJ 341
Watson M, Lucas C, Hoy A, Back I (2005) Oxford Handbook of Palliative Care. *Oxford University Press*

The Gold Standards Framework Centre CIC
info@gsfcentre.co.uk www.goldstandardsframework.org.uk +44 (0) 1743 291 891 / 367 066