

Palliative Care at Home



**VICTORIA
HOSPICE**



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Victoria Hospice Society

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Island Health.*

Your Professional Care Team at Home

Team member	Name	Phone number
Home and Community Care nurse		
Family physician		
Home support agency		
Community nutritionist or rehabilitation therapist		
Faith community		
Victoria Hospice staff (e.g., counsellor, volunteer)		250-370-8715
Case manager (if applicable)		
Non-emergency falls assistance		

➔ Assistance from 8:30 am to 4:30 pm:

Call your Home and Community Care nurse or family physician (above)

➔ Assistance after 4:30 pm:

Evenings 4:30 pm to 10:00 pm (Home and
Weekends 8:30 am to 10:00 pm Community Care) _____

All nights 10:00 pm to 8:30 am (Victoria Hospice) 250-370-8715

➔ Urgent Issues – Any time, day or night:

Call Victoria Hospice: 250-370-8715

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About This Binder

Palliative Care at Home is for you, your family, and your other caregivers to use while you are registered with the Victoria Hospice Palliative Care Program and Home and Community Care Nursing. The binder is intended to empower you by providing information and education that will allow you to make sound choices throughout your illness.

Palliative Care at Home will improve communication and planning around your care. Rather than explaining your situation to every new person, you will be able to refer him or her to the information already contained in this binder. Each family member and caregiver will be able to quickly see what has been recommended or ordered for you, and the reasons for any changes that have been made. It will be easier for the whole team to work together.

We believe that the more information you, your family and your other caregivers have, the better able you will be to decide what is important: what you need and what you want. Having these resources at your fingertips will allow you to make informed choices about your care.

The binder is divided into several sections. You may find some sections more interesting and useful to you than others; however, all the material is here for you, your family and your caregivers to look through. If you have any concerns or questions, please do not hesitate to discuss them with your Home and Community Care nurse, family physician or Victoria Hospice.



Hospice Registration Information

Victoria Hospice is a community-based palliative care program which enhances the quality of life and death for people facing death and bereavement.

Victoria Hospice supports the rights of individuals and families:

- ☐ To maintain individuality and dignity
- ☐ To know and discuss, in whatever terms they wish, the extent of the disease and its implications
- ☐ To be involved, according to desire and ability, in the planning and choice of care

You are eligible to register* with Victoria Hospice services if you meet the following criteria:

- ☒ You live in an area of the Vancouver Island Health Authority served by Hospice
- ☒ The intent of your care is palliative (i.e. comfort-oriented only and will not involve life-prolonging procedures)
- ☒ Your Family Physician agrees that Hospice services are appropriate and desirable
- ☒ You are willing to accept added care in the home, if necessary, from community support systems, including Home and Community Care Nursing and Community Health Workers
- ☒ You are currently residing at home or in an Assisted Living Facility

Note:*You may register before actually requiring services.

If you do not have a Home and Community Care Nurse at this time, please ask your Family Physician to call Central Intake and request a Home and Community Nursing Care visit.

Your Home and Community Care Nurses will arrange a visit with you and complete the Victoria Hospice registration. At this time the nurse will provide more detailed information about the services Victoria Hospice offers. After consulting with you, she will request the appropriate services as required.

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Your Care Team at Home

Your care team includes everyone who has a part to play in your care. It will include you, your immediate family members and other caregivers, as well as your family physician, Home and Community Care nurse, community health worker, and Victoria Hospice staff. It may also include a case manager, occupational therapist or physiotherapist, dietician, and/or social worker. The care you receive is enhanced when we all work together.

These sections explain what the different team members do and what you might expect from them. If you are still unclear about someone's job, ask your Home and Community Care nurse for more information.

Patient

As the patient, **you are the focus of care**. You can expect to receive skilled and coordinated care that addresses all aspects of your life: physical, emotional, spiritual and social support that respects your needs and wishes.

You can decide how involved you want to be in the planning and provision of your care. Early planning gives you time to look at all the options and make the best decisions possible. This means that you need to be honest and let others know what you want and need, both now and in the future. If it is hard to sort out exactly what you need, ask for help.

When you get into any kind of difficulty, you should ask for help immediately. Little problems are much easier to solve than big crises, for both you and the others on your team.

This binder has been designed for you and your family to use. It contains instructions for care, information about a variety of topics, and tools to help you arrange your future plans. Check with your Home and Community Care nurse if you have any questions about or problems using the binder.

Family and caregivers

The term "family and caregivers" includes immediate family, relatives, friends and other people closely involved with the patient.

As family, you are seen as part of the team, according to the patient's and your own wishes. You will receive support services directed toward your particular needs. This means it is important for you to let us know what you want and need during this time. You may also be included in discussions about issues related to the patient's care, such as symptom management, estate and funeral planning, and future care options.

It is important that you consider accepting some help with the care you are providing. If you don't look after yourself, you run the risk of becoming sick and exhausted and then may be unable to care for the patient.

Family physician

Your family physician is the **primary medical person** involved in your care at home and is the first person you call with any medical concerns. Your family physician can visit you at home, refer you to other community caregivers for help with your care, and/or be available to provide family support and information.

Vancouver Island Health Authority Home Health Services

Home and Community Care nurse

Your Home and Community Care nurse will coordinate care in the home. The nurse may provide nursing care, provide information about patient care and health, request other services (such as Victoria Hospice and other community professionals), arrange supplies and home aids, and provide support for you and your family. With you, your Home and Community Care nurse will determine the need for and frequency of nursing visits.

You will be supported by a home care nursing team providing service seven days per week. If you need to contact a nurse outside of regular office hours, telephone the number on the “Your Professional Care Team at Home” sheet in the front pocket of this binder. If the nurse is unable to take your call, leave a message on the answering machine. The nurse will return your call as soon as possible.

Physiotherapy and occupational therapy

This is a non-urgent, home-based rehabilitation service of the Vancouver Island Health Authority that provides consultation, assessment, treatment and education by physiotherapists and occupational therapists. Services for palliative care patients may include help to maintain independence and conserve energy, specialist pain management, stress management, and assessment of home safety and equipment needs.

Case management

A case manager can help you apply for a number of services, such as adult day centres, respite and placement in a long term care facility. If you need respite care or permanent placement in a long term care facility (nursing home), your case manager will help with

arranging this. You may have to pay a fee for some of these services, based on a financial assessment.

Home support

Your Home and Community Care nurse will contact the home support agency that provides services in your neighbourhood and ask them to telephone you. Home support agency offices have supervisors who are responsible for assigning, scheduling and supporting their community health workers.

Community health worker

The community health worker will help family members and caregivers with specific tasks in caring for the patient. It is important for you to think about what help you need before the community health worker starts. Discuss this with your Home and Community Care nurse in order to determine what help can be arranged for you.

As a general rule, community health workers **can** provide companionship; help with bathing, dressing and feeding; spend the night; and give family members some respite time. There are also some nursing tasks that workers can do with the approval and supervision of your Home and Community Care nurse.

Workers **cannot** iron, look after pets, provide transportation or attend to business matters. You may have more than one community health worker, depending on the amount of care you require.

You may wish to hire someone through a private agency or the newspaper to help with household chores or personal care.

Victoria Hospice

Victoria Hospice is a *program* of care rather than a *place*. The care we offer is called “palliative care,” which means it is oriented toward providing comfort rather than active/curative treatment of disease. Our goal is to support each family member through this time of illness, death and bereavement according to their needs and wishes.

We offer skilled and compassionate medical and nursing care, together with social, emotional and spiritual support from professional and volunteer caregivers. We will focus on your **care and comfort, rather than cure**. This means that we will work to control symptoms that may interfere with your daily living, rather than trying to cure your disease. In doing so, we will maintain a respect for your right to be a person, rather than just “a patient” or “a family.”

There are people at Victoria Hospice who can be of assistance in all of these areas. Our team includes nurses, doctors, counsellors, volunteers, and spiritual care and administrative staff.

As a community-based palliative care program that enhances the quality of life and death for people facing death and bereavement, Victoria Hospice supports the rights of individuals and families to:

- maintain individuality and dignity
- know and discuss, in whatever terms they wish, the extent of the disease and its implications
- be involved, according to desire and ability, in the planning and choice of care.

People who register with Victoria Hospice:

- want care that is palliative (i.e., it is comfort-oriented and may not involve life-prolonging procedures)
- have a family physician who agrees that Victoria Hospice services are appropriate
- are willing to accept support from the Vancouver Island Health Authority (VIHA) Home and Community Care Team if needed, including Home and Community Care nurses and community health workers
- currently live at home or in an assisted living facility.

Medical consultation

There are palliative care physicians who work exclusively with Victoria Hospice. Their job is to advise on the medical care of patients and to act as consultants for your family physician when necessary. Their goal is to develop a plan of action that will ensure that you have the most comfort possible throughout your illness. They may visit you in hospital or at home, or you may see them at the Victoria Hospice Palliative Care In-Patient Unit. A palliative care physician consult may be requested by your family physician or the Home and Community Care nurse or Palliative Response Team.

There is also a small group of family physicians from the community who work with Victoria Hospice. They have all completed an extensive training program in palliative care and work with us in our on-call group. This allows us to offer 24-hour medical backup for your family physician, the Home and Community Care nurse, the Victoria Hospice Palliative Care In-Patient Unit and the Palliative Response Team.

Palliative Care In-Patient Unit

The Victoria Hospice Palliative Care In-Patient Unit is located on the third floor of the Richmond Pavilion at the Royal Jubilee Hospital. It is a 17-bed unit comprising 7 acute palliative beds, 9 hospice beds and 1 respite bed. There are 11 single rooms and 3 double rooms. Patients are often moved from one type of room to another based on the current needs of the unit as a whole.

There is a rooftop garden located on the fourth floor. Visiting hours are unrestricted. Pets may visit, provided there is family supervision.

Acute palliative beds are used for two purposes. One is to provide symptom management with 24-hour professional care, with the goal of resolving the symptoms and the patient

then returning home. The other purpose of an acute palliative bed is to support imminent death when care at home is no longer possible or is not wished for.

Hospice beds are used when care for a patient cannot continue at home or when a patient in an acute care bed in hospital or at Victoria Hospice is unable to return home. Prognosis is generally thought to be about six weeks. If the patient's condition stabilizes or improves after admission, further planning may be done with consideration for discharge home or placement in an alternative community facility.

Hospice beds are provincial beds and have a daily cost attached to them. You will be asked to sign the End-of-Life Long Term Care Agreement (a provincial document) and will receive a bill from the Vancouver Island Health Authority (VIHA).

Palliative Response Team (PRT)

The Palliative Response Team (PRT) provides short-term crisis treatment for physical/emotional symptoms that might otherwise require hospital admission. The team is also available to help support a death at home.

The PRT is staffed by a nurse and counsellor, with backup from a palliative care physician. There is one team to serve the Greater Victoria area. Nursing coverage is 24 hours per day (with occasional exceptions).

Your family physician or Home and Community Care nurse usually requests the PRT, but referrals can be made by any professional team member.

When the PRT receives the request, they will telephone and make arrangements to come to your home. The PRT will then be in daily contact with you and will work with your Home and Community Care nurse and family physician until symptoms have resolved, other plans have been made, or death has been supported at home.

Emotional, spiritual and psychological support

Support before a death

Counselling

Often the emotional pain and stresses associated with advancing illness or death can be as difficult to deal with as the physical symptoms. You may need strategies for managing the stress of caregiving. You may wonder where to get help with finances and estate planning or how to talk to your family about difficult issues, such as funeral arrangements. Or you may simply need someone to talk to.

Victoria Hospice counsellors are available to visit you in your home or at our Palliative Care In-Patient Unit to help with these kinds of concerns and questions. They can also help you

communicate with your health care team and others about issues of concern, and help you plan for changing care needs.

If you need assistance with **family issues**, our counsellors can help you address difficult subjects and unfinished business and deal with the challenges of caregiving and decision-making. They can also facilitate family meetings.

Victoria Hospice counsellors provide **emotional support**, helping you to deal with the many losses and changes that occur during illness, and to address questions of meaning, legacy and spirituality and the many complex thoughts and feelings that arise at this time.

Finally, our counsellors provide **education**, sharing information about what to expect and how to prepare for what's ahead, and offering self-care strategies.

Child and youth counselling

If you have concerns about the children in your family and how to support them before and after death, our specialized child and youth counsellor is able to meet with you. We can also provide you with written materials. In addition, we frequently offer support groups for parents/guardians and children.

Spiritual and religious care

At Victoria Hospice, we value the role of spiritual and religious care at the end of life. Our Spiritual and Religious Care Coordinator and a team of volunteers offer spiritual support to patients and family members of all faiths, cultures and beliefs, whether you are at home or in the Palliative Care In-Patient Unit.

Spiritual and religious care support includes:

- exploring questions of belief and making sense of life and death
- supporting family members when there are concerns about religion or spirituality
- offering prayers, blessings and rituals according to your beliefs
- helping to connect with a faith or spiritual tradition that has meaning for you
- assisting in planning funerals, memorials or other rituals to mark times of loss and change
- at your request, referral to your particular religious or faith community.

Bereavement

Throughout the first year after a death, Victoria Hospice continues to offer care for family members and friends through bereavement services. There is a range of available supports, such as counsellor and volunteer support in person or by telephone, and a variety of groups.

The counsellors are trained and experienced in bereavement counselling with individuals, families, children and youth, and groups. Information on grief and bereavement and referrals to other community services are also available.

Support for children and youth, along with spiritual and religious care, are also available to family members after a death.

Please see section 5 of this binder, Bereavement – For Family and Caregivers, for further information.

Volunteers

Community volunteers

Community volunteers can be requested to provide practical, emotional and social support for patients and families registered with Victoria Hospice, to supplement and enhance the care provided by other members of the team.

Community volunteers offer the kinds of services that a neighbour or friend might provide. Possibilities include:

- someone to talk to and for friendly visiting
- someone for companionship when a person is feeling isolated, alone or anxious, or when conversation is unnecessary but a friendly presence is supportive
- involving a patient or family member in activities (e.g., board games, cards, puzzles, reading, singing, writing a card/note, scrapbooking)
- providing a short period of respite for family members
- providing complementary therapy (e.g., reiki, therapeutic or healing touch)
- accompanying a patient or family member on a short walk or outing.

Community volunteers do not provide personal care or do housekeeping tasks. If these services are required, a family can arrange for them by speaking to the Home and Community Care nurse.

Palliative Care In-Patient Unit volunteers

Volunteers on the Palliative Care In-Patient Unit are essential members of the clinical team. The role of volunteers is to:

- assist the other members of the team, primarily the nursing staff, in carrying out tasks that support quality patient care
- maintain a supportive, compassionate and welcoming environment
- provide services that enhance the care of patients, including:
 - hospitality services for patients, families and visitors
 - complementary therapy (e.g., reiki, therapeutic touch, healing touch, pet visiting and bedside singing)
 - access to books, audio and video materials from a lending library
- be available to visit with patients, family members and visitors, providing emotional and spiritual support
- engage in activities (e.g., listening to music, reading, playing board games or cards, doing puzzles, singing)
- sit with or provide companionship for patients.

Life Stories

Life Stories offers an opportunity for patients registered with Victoria Hospice to record their life stories, thoughts or special memories on CDs.

A trained volunteer interviewer gently guides the conversation, giving you a chance to talk about the important things in your life. You decide what you want to talk about. The interview lasts about an hour, but it can be shorter, depending on your energy level. The interviews are recorded on digital audio and you can use up to five hours of recording time in total. When all the interviews have been completed, they will be transferred, in their entirety (i.e., with no editing), to audio CDs.

This free service can be accessed through your Home and Community Care nurse while you are at home or through any staff member while you are on the Palliative Care In-Patient Unit.

To request Victoria Hospice services

If you or your family wish to request a specific Victoria Hospice service, please let your Home and Community Care nurse know. She will contact Victoria Hospice to arrange for the specific service you require. Sometimes your nurse or family doctor will suggest a particular Victoria Hospice service that would be helpful for you. For any urgent needs after hours, please call Victoria Hospice.

Costs of Care

What your B.C. health insurance covers and does not cover

The Medical Services Plan (MSP) provides excellent overall coverage for you and your family. The premiums required vary according to your age and ability to pay.

Costs that are covered

There are many aspects of your care that you do not have to pay for directly, including:

- VIHA Home and Community Care staff
- family physician visits
- Victoria Hospice staff visits
- lab tests and X-rays
- hospital admission
- Victoria Hospice Palliative Care In-Patient Unit acute palliative beds only
- medications and equipment that are covered by the BC Palliative Care Benefits Program.

Costs that are partially covered

You may be required to pay for portions of some things, depending on your age and premiums. Examples are:

- home support services that may not be covered by the BC Palliative Care Benefits Program
- hospice bed at Victoria Hospice or any other facility
- respite bed at Victoria Hospice or any other facility.

Costs that are not covered

There are several things that are **not** covered by insurance, including:

- some prescription medications not covered by the BC Palliative Care Benefits Plan (see below)
- some equipment and delivery costs for equipment
- British Columbia Ambulance Service
- transportation.

The BC Palliative Care Benefits Program

The BC Palliative Care Benefits Program was developed to support individuals of any age who have reached the end stage of a life-threatening disease or illness. Through this program, BC residents who wish to receive palliative care services at home can receive assistance from the provincial government with the cost of selected medications and certain medical equipment and supplies, and home supports. The family physician determines the patient's eligibility for the benefit plan and completes the required paperwork.

For more information, call 1-800-663-7100 or go to www.health.gov.bc.ca/pharmacare/outgoing/palliative-patientinfo.pdf.

Financial assistance

Questions?

If you have any questions about or problems with your health benefits, income or expenses, a VIHA social worker or Victoria Hospice counsellor can provide practical help and information.

Canada Pension Plan

A disability pension is available to Canada Pension Plan contributors who are under the age of 65 and have a severe and prolonged disability.

For more information, call 1-800-277-9914 or go to www.servicecanada.gc.ca/eng/isp/cpp/disaben.shtml.

Canada Revenue Agency

There are provisions to obtain income tax deductions for people who have been “disabled” for an extended period of time, their dependants and their medical expenses. To claim these deductions, you must complete Revenue Taxation Form T2201.

For more information, call 1-800-959-8281 or go to www.cra-arc.gc.ca/disability.

Canadian Cancer Society

The Canadian Cancer Society has an Emergency Aid Program that provides financial help with medical equipment, some prescribed medications, transportation, lodging, and so on. Eligibility for the program is determined through a means test.

For more information, call 250-592-2244.

Community organizations

If you are a member of a community organization, association or lodge, check to see if it provides financial assistance during a member’s illness.

Employment Insurance benefits

You may qualify for Employment Insurance benefits.

For more information, call 1-800-206-7218 or go to www.servicecanada.gc.ca/eng/ei/types/sickness.shtml.

Employment Insurance compassionate care benefits

Employment Insurance also provides compassionate care benefits for people who have to leave work temporarily to provide care or support for a family member who is dying.

For more information, call 1-800-206-7218 or go to www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml.

Extended health plan

If you have an extended health plan, check to see what expenses may be covered (e.g., nursing care, community health worker, medications, oxygen).

Fair PharmaCare

Fair PharmaCare helps eligible British Columbians with the cost of eligible prescription drugs and designated medical supplies. Coverage is based on income.

For more information, call 1-800-663-7100 or go to www.health.gov.bc.ca/pharmacare/plani/planiindex.html.

Guaranteed Income Supplement

Depending on your income, you may be eligible for the Guaranteed Income Supplement. For example, if your only income is the Old Age Security pension, you would most likely qualify.

For more information, call 1-800-277-9914 or go to www.servicecanada.gc.ca/eng/isp/pub/oas/gismain.shtml

Income Assistance

If you receive social assistance, then you may qualify for financial help with medical expenses, prescriptions, and special health needs.

If you do not already receive social assistance, but you do have a low income, you may also be able to get help with certain expenses.

For more information, call 1-866-866-0800 or go to www.eia.gov.bc.ca/bcea.htm.

Life insurance policies

If you have a serious illness, it may be possible to apply to have your premiums waived without affecting the policy itself. This requires a written application and medical proof of illness.

Veterans Affairs Canada

If you are a veteran, you may be eligible for:

- an attendance allowance for care given while you are ill
- a disability pension
- equipment and home alterations
- an oxygen subsidy
- home maintenance.

For more information, call 1-866-522-2122 or go to www.veterans.gc.ca/eng/services. (It will be helpful to know your service number when you call.)

Equipment and Transportation

Home aids and equipment

You may need home aids and other equipment to make patient care at home safe and easier.

Some items can be loaned from the Red Cross, Mt. Newton Centre and Westcom Medi-Lend, free of charge. It is the family's responsibility to arrange for pick-up and return of items.

Many home aids are also available through the BC Palliative Care Benefits Program.

Some equipment must be ordered by a health care professional. Please speak with your Home and Community Care nurse.

Canadian Red Cross Society – Health Equipment Loan Program (HELP)
909 Fairfield Road, Victoria
250-382-2043
www.redcross.ca/article.asp?id=3188&tid=080

Mt. Newton Centre Society
2158 Mt. Newton Cross Road, Saanichton
250-652-2112
www.mountnewtoncentre.org/programs_outreach_mels.html

Westcom Medi-Lend Society
1098 Goldstream Avenue, Langford
(Inside the main entrance to Priory Hospital. Watch for signs.)
250-478-5373

Transportation

When you are no longer able to drive or get around in your usual ways, transportation can be difficult. When you are used to being independent, it may feel awkward to ask others to drive you to the store or to appointments. However, this is the kind of task that family members, friends and acquaintances often like to take on.

If you do not have anyone who is able to transport you, there are a few services available. There is a charge for most of these.

Wheelchair or stretcher transfer:

- Non-emergency ambulance: 250-727-2400
- Medi-Van: 250-389-0948

HandyDART (wheelchair-accessible vans with power lifts):
250-727-7811
www.transitbc.com/regions/vic/accessible/handydart-serviceinfo.cfm

Taxis:

Listed in the Yellow Pages of the phone book under "Taxicabs"

Transportation to Cancer Clinic appointments provided by volunteers:

250-414-4250

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Planning Ahead

You and your family may choose to make some decisions and arrangements ahead of time, in order to:

- ensure that your wishes are known and respected
- reduce the number of decisions that will need to be made immediately after death
- provide an opportunity for you and your family to talk about arrangements, concerns and feelings
- allow you to leave your affairs in order for your family
- reduce family stress during the early hours and days of grief.

This section of the binder is intended to help you make these decisions and arrangements, and covers some of the practical things you need to think about. It is always easier to deal with situations if you know what to expect, what to do, and who is available to you.

If you want to discuss estate matters, memorial or funeral arrangements, or emotional or family concerns, a Home and Community Care social worker or a Victoria Hospice counsellor can meet with you.

You may find it helpful to have a support person who can spend time with patients and families. Victoria Hospice has volunteer staff who will visit families on a regular basis.

If there are spiritual issues that arise for any of you or you want help with a memorial or funeral service, you may want to contact your spiritual advisor. The Victoria Hospice Spiritual and Religious Care coordinator can also help you with these matters, especially if you do not belong to a particular religious or faith community.

All of the members of your care team are experienced with death at home. Their job is to help you and your family look at all the options, make the best decisions possible and prepare accordingly.

Advance care planning

Advance care planning is the process a capable adult follows to ensure that his or her beliefs, values and wishes for future health care are known in the event that he or she is incapable of making health care decisions when care is required.

A guide to advance care planning is available on the Vancouver Island Health Authority (VIHA) website, at www.viha.ca/advance_care_planning.

Completing estate plans

Having your legal and financial affairs in order will help your family members take care of estate matters after your death. If you do not already have a will, consider getting one, to ensure that your family is not left with legal issues around the disbursement of your assets. Without a will, your family will have to apply to the Supreme Court of British Columbia for

the right to administer your estate. Your assets will then be determined by law rather than by your wishes.

For more information, request the **Estate Planning Package** available from Victoria Hospice or your Home and Community Care nurse.

Pronouncement plan

Talk to your family physician or Home and Community Care nurse about who will come to your home (day or night) to pronounce the death, provide support and guide family members and caregivers through the next steps.

You may be able to waive the visit for pronouncement. In this case, there are a few things that must be done **beforehand**:

- The family physician:
 - determines that this is a case of an expected, planned home death, and completes a “Notification of Expected Death” form
 - faxes the completed “Notification of Expected Death” form to the funeral home of choice
 - completes a “No Cardiopulmonary Resuscitation” form or a “MOST” (Medical Orders for Scope of Treatment)
 - informs the Home and Community Care nurse of the pronouncement plan
 - agrees to be available to complete the Physician’s Certification of Death within 48 hours of the patient’s death.
- Family members and caregivers are instructed not to call 911. (Police, ambulance and coroner are not required to be called for or notified of an expected death at home.)

At the time of death, family members and caregivers are required to wait for **one hour** after breathing has stopped before calling the funeral home to transport the body.

If family members or caregivers change their minds at the time of death and request a visit for pronouncement and support, they may call the family physician, Home and Community Care nurse or Victoria Hospice. (It is important to recognize, however, that an immediate response may not be possible.)

Support

If you wish to have family, friends or a spiritual advisor to be with you during the last few days or hours, arrange this ahead of time.

Organ donation

Discuss your wishes for any donation of organs with your family physician or Home and Community Care nurse. There are some restrictions based on age and cause of death, and there may also be some costs.

BC Transplant
1-800-663-6189
www.transplant.bc.ca

Eye Bank of BC
Jim Pattison Pavilion North B-205
Vancouver General Hospital
855 West 12th Avenue
Vancouver, BC V5Z 1M9
Phone: 1-800-667-2060 or 604-875-4567
Email: eyebankofbc@vch.ca
www.eyebankofbc.com/how.html

UBC Body Donation Program
Department of Cellular and Physiological Sciences, UBC
2350 Health Sciences Mall
Vancouver, BC V6T 1Z3
Phone: 604-822-2578
Fax: 604-827-4209
Email: body.program@ubc.ca
Information and consent forms can be obtained at:
<http://cps.med.ubc.ca/bodyprogram/>

Memorial/Funeral Plans

Prearranging your memorial or funeral service can help avoid difficult decision-making and emotional stress for family members after your death.

The first step is to make an appointment with a funeral director to complete your arrangements. (A list of funeral facilities is included on page 5 in this section of the binder.)

Things to consider:

- Will there be a service?
- When will the service be held?
 - Will people be coming from out of town?
 - Would a weekday or weekend be better?
- What kind of service?
 - funeral
 - memorial
 - other
- Where will the service be held?
 - church, chapel
 - funeral facility
 - home, garden

- Who will officiate?
 - spiritual advisor or clergy
 - friend
 - family members
- Burial or cremation?
- If you prefer cremation, will your remains be buried, scattered or placed in a columbarium?

Other preferences (e.g., music, readings, important rituals) should be arranged with the funeral director, a family member or officiating person.

It is helpful to attach a copy of your wishes to your will and give a copy to your family or executor.

For more information and help with prearrangements, request the **Memorial/Funeral Planning Package** available from Victoria Hospice or your Home and Community Care nurse.

Funeral facilities

Care Funeral Services	2676 Wilfert Road Victoria 250-391-9696	http://carefuneral.com/
	9787 Fourth Street Sidney 250-655-9669	
Earth's Option Cremation and Burial Services	10 Kaleigh Lane Victoria 778-440-8500	www.earthsoption.com
First Memorial Funeral Services	1155 Fort Street Victoria 250-384-5512	www.firstmemorial.ca
	4725 Falaise Drive Saanich 250-658-5244	
McCall Brothers Funeral Directors	1400 Vancouver Street Victoria 250-385-4465	www.mccallbros.com
Pacific Coast Cremation	3212 Jacklin Road Victoria 778-433-9344	pacificcoastcremation.com
Sequoia Gardens Memorial Funeral and Cremation Services	4665 Falaise Drive Saanich 250-658-6202	www.mccallbros.com
Sands Funeral Home	307 Goldstream Avenue Colwood 250-478-3821	sandsfuneral.com
	1803 Quadra Street Victoria 250-388-5155	sandsfuneral.com
Simply Cremations and Funeral Service	2-2075 Henry Avenue West Sidney 250-656-5555	www.simplycremations.com
Victoria Cremation Service	317 Goldstream Avenue Victoria 250-391-6294	www.victoriacremations.ca/

Note: This information is current as of October 2014.

3. Patient Care – For Patient, Family and Caregivers

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Self-Assessment, Reflection and Self-Care

The months and weeks before death offer an opportunity to look back and understand what our life has been about. It can be a time of gaining wisdom about the meaning of life or spirituality, of discovering and understanding our strengths, of learning to accept love and caring from others. It can also be a time to make peace and heal difficult relationships. Dying is a great mystery, and maintaining our curiosity and willingness to learn about it can help people can make the experience a valuable and important part of living. However, it is also a time of change, loss and grief.

This part of the binder provides some information about **what to expect** during this time at an emotional, spiritual and practical level. You will find **self-assessment tools** for both patients and family members and caregivers, along with several **reflection exercises** that offer you an opportunity to stop in the midst of all that is going on and reflect on how you are doing, what questions you may have, or what things you may want to say to those who care about you. You can use the space provided to make notes, or you might prefer to think privately about the statements and questions. There are a number of ideas to help you with **stress reduction, relaxation and caring for yourself**. There is also a list of **question prompts** to help you talk to your care team.

If you would like **professional support** at this time, talk to your family physician or Home and Community Care nurse, or ask the nurse to request a visit from a Victoria Hospice counsellor.

For the patient

Reflection

Take a moment to complete the following statements.

The most important things to me right now are

I find joy in

I am hoping for

Things I want my family to know – for example, about my care, how I'm doing, my thoughts and feelings, what's important to me

Patient self-assessment

For each item, please indicate how much of a problem or concern these have been for you in the last few days.		Not a problem	A slight problem	A problem	A major problem	An overwhelming problem
1.	Not being able to carry out tasks associated with daily living (e.g., washing myself, getting dressed)	1	2	3	4	5
2.	Not being able to attend to my bodily functions independently (e.g., needing assistance with toileting-related activities)	1	2	3	4	5
3.	Experiencing physically distressing symptoms (e.g., pain, shortness of breath, nausea)	1	2	3	4	5
4.	Feeling that how I look to others has changed significantly	1	2	3	4	5
5.	Feeling depressed	1	2	3	4	5
6.	Feeling anxious	1	2	3	4	5
7.	Feeling uncertain about my health and health care	1	2	3	4	5
8.	Worrying about my future	1	2	3	4	5
9.	Not being able to think clearly	1	2	3	4	5
10.	Not being able to continue with my usual routines	1	2	3	4	5
11.	Feeling like I am no longer who I was	1	2	3	4	5
12.	Not feeling worthwhile or valued	1	2	3	4	5
13.	Not being able to carry out important roles (e.g., spouse, parent)	1	2	3	4	5
14.	Feeling that life no longer has meaning or purpose	1	2	3	4	5
15.	Feeling that I have not made a meaningful and/or lasting contribution in my life	1	2	3	4	5
16.	Feeling that I have “unfinished business” (e.g., things that I have yet to say or do, or that feel incomplete)	1	2	3	4	5
17.	Concern that my spiritual life is not meaningful	1	2	3	4	5
18.	Feeling that I am a burden to others	1	2	3	4	5
19.	Feeling that I don’t have control over my life	1	2	3	4	5
20.	Feeling that my health and care needs have reduced my privacy	1	2	3	4	5
21.	Not feeling supported by my community of friends and family	1	2	3	4	5
22.	Not feeling supported by my health care providers	1	2	3	4	5
23.	Feeling like I am no longer able to mentally cope with the challenges to my health	1	2	3	4	5
24.	Not being able to accept the way things are	1	2	3	4	5
25.	Not being treated with respect or understanding by others	1	2	3	4	5

Used with permission: Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, Sinclair S, Murray A. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage. Dec;36 (6):559-712008

Focus on the patient

Physical changes

As your illness progresses, you may have symptoms such as pain, nausea or shortness of breath. This likely means you also have more medications, tests or treatments to deal with. You may find that you have less energy, sleep more and are less interested in food and eating. You may find it difficult to get out of bed or walk far. You may notice various changes in how your body looks or functions. These many changes can be overwhelming and leave you feeling out of control, anxious or even frightened. You may find that this is also worrisome for your family.

Reflection

Take a moment to complete the following statements.

Things that worry me right now (my greatest fears) are

I feel overwhelmed by

I would like to talk to my family about

I would like to talk to my care team about (see the "Question prompt list" at the end of the Self-Assessment, Reflection and Self-Care section)

Life changes

At this time you may experience changing thoughts, feelings and levels of energy that affect you and those around you. As a result, you may notice that your usual activities, interests and relationships are shifting. More and more, your focus is on daily care, symptom management and planning for future care needs. Everyone is becoming more tired and stressed, and there are many changes to family roles and duties. You may find that your world is “shrinking,” as you have less energy for social interactions, or that there are more phone calls and interruptions to your daily life, with increased numbers of visitors and health professionals in your home.

In the midst of these changes and activities, it is important to take some time out for yourselves as a family and as individuals. It is okay to cancel or delay visits when you don’t have the time or energy for extra people. It is okay to need time on your own, whether for rest, exercise or hobbies.

Reflection

Think about the many changes that you and your family have experienced.

List five ways in which your focus has changed over the past months, weeks or days.

What do you miss most right now about your day-to-day life?

What are you feeling right now?

Losses

You may find that you are losing many important things in your life – independence, physical abilities and fitness, appetite, connections with colleagues and friends, hobbies, roles and so on. It may be hard to depend on others to run errands, cook and clean, and, perhaps, provide personal care (such as bathing or eating). It can be hard to see your spouse doing jobs or tasks that previously you would have done. On the other hand, you may feel relieved that you are no longer required to do some things. Whatever your reaction, it is to be expected that these losses will affect you and your family, and you may find it helpful to talk to someone. Your family physician, Home and Community Care nurse or Victoria Hospice counsellor are available for support.

Reflection

Think about recent losses in your life and how you are coping with them.

How do you express your thoughts and feelings about these losses?

How are you coping with these losses? For example, do you find you need to talk to others or do you prefer to work things through on your own?

How do your family members express their grief differently from you? Is this a problem?

Reactions

Since your diagnosis, you will have experienced many different thoughts and feelings. Anger, hope, sadness, gratitude, depression, joy, despair, fear and love are all possible, even expected. Some emotions will come and go, while others may stay with you for long periods of time. Old feelings and issues could rise to the surface again, or you may worry about the future, for yourself or your family. Your memory and concentration may be poor, and making decisions might be difficult. You may be preoccupied with thoughts about your illness or death. You may find that you are questioning your beliefs or looking for spiritual peace. You may find yourself hoping for a miracle or grieving the loss of a life's dream.

Reflection

Think about your thoughts and feelings over the past days, weeks or months.

Do you have any concerns?

What would be helpful to you now? (For example, information, help with a task, talking to someone.)

List three things you are grateful for.

Care for the spirit

With your physical symptoms addressed and a level of comfort achieved, you may find a space cleared to explore personal healing, repair and growth. You may have religious beliefs and practices that give you comfort and guidance or a particular philosophy of life that directs your exploration. Or you may have no connection with a power or life force beyond that of your everyday life. Regardless, questions around purpose and meaning of life, mortality and legacy often surface as we confront the prospect of death – our own or that of someone we love.

Reflection

As you consider the end of life:

What meaning has your life had, for you or for others? What is your legacy?

How do you think about your spirit?

Do you need to seek or offer forgiveness?

How has your faith or courage been tested over the past weeks or days?

Is there a religious or spiritual ritual that would give you comfort now?

Do you sometimes feel lonely or isolated?

Patient resilience: Strategies for self-care

Relaxation techniques¹

The following exercises have been developed to help with sleep, breathing, anxiety, pain and general relaxation. You can practise them alone or have someone read the instructions to you. It may be helpful to first practise these techniques when you are already relaxed and able to focus on the instructions. Family members may also find these helpful.

Sleep meditation (for deep relaxation)

This simple technique can prepare your body and mind for restful sleep.

- Close your eyes softly and bring your attention to your heart.
- With inner awareness on your heart, mentally feel the area around your heart and silently say, “one.”
- Now bring your attention to your left shoulder and silently say, “two.”
- Next let your attention come to your left hip. Mentally feel the hip and silently say, “three.”
- Continue through the body, bringing awareness to and mentally feeling the following parts as you count them: navel “four,” right hip “five,” right shoulder “six” ...
- Let attention come back to your heart again for “one” and so on, moving your awareness at a comfortable and relaxed pace, simply noticing and mentally feeling each part as you count it.
- Let your mind “busy” itself by slowly moving in this pattern; it will soon tire and spiral inwards to come to rest at the heart, its settling place for sleeping. As you begin to drift off, simply let go of the practice and sink into sleep.

Relief breath (for pain, stress or anxiety)

This exercise can increase feelings of safety and your ability to deal with challenging situations.

- Begin by slowing your exhale slightly by breathing out through softly pursed lips.
- Let your belly draw back and widen with each exhale.
- To inhale, close your lips and release any belly tension – this relaxing will allow the most natural in-breath possible to flow through your nostrils and into your lungs.
- Over time, gently lengthen the exhale to a count of 6 or 8, and inhale for a count of 3 or 4.
- Allow the out-breath to be intentional and complete without strain, and the in-breath to be as relaxed and effortless as possible.
- Continue for as many rounds as desired.

¹ Developed by M. Butot from C. Johnson & D. Webster, *Re-crafting a life: Solutions for chronic pain and illness* (2002, Brunner-Routledge) and K. McGonigal, *Yoga for pain relief: Simple practices to calm your mind and heal your chronic pain* (2010, New Harbinger).

Anxiety reduction breathing (in – cool, out –warm)

This technique stimulates the parasympathetic nervous system – activating the body’s natural relaxation response. It can be used when you are alone or while waiting for medication to take effect and can be practised at any time and anywhere.

- Bring your attention to the breath, just as it is, allowing your body to breathe in its own way.
- Let your attention come to your nostrils or the back of the nose, wherever the sensation of air moving is strongest and **feel the breath moving** there.
- Begin to notice the temperature difference between **in-breath (cool)** and **out-breath (warm)** and pay attention, feeling this difference for one to several minutes.
- If you like, silently repeat to yourself “in – cool, out – warm” to deepen the effect.
- Allow a few minutes for the practice to do its work, assisting your body’s own relaxation response to help distress and anxiety subside naturally.
- When you feel finished, count yourself up through five regular or deeper breaths, becoming increasingly alert and refreshed at each breath.

Eye breathing (for acute pain or anxiety)

This exercise can help separate you from feelings of pain or discomfort or from disturbing thoughts. It can be used in emergency situations and in times of acute pain or anxiety while waiting for medical interventions to take effect.

- Sit or lie as comfortably as you are able, breathing as normally as possible.
- Begin to link your eyes closing with your breathing rhythm, just as your breath is right now: **open your eyes while breathing in and allow them to close while breathing out.**
- Continue breathing, establishing a distinct rhythm all your own.
- As you inhale (eyes open) and exhale (eyes closed), you may want to imagine adding a colour to the inhale – any colour that you find soothing or healing, a colour that offers the kind of peacefulness and comfort you are looking for.
- After a while, you might consider colouring the exhale as well – any colour that represents something you want to eliminate or release.
- Continue breathing – (eyes open) breathing in that healing colour, (eyes closed) breathing out that releasing colour – for as long as needed.

Pursed-lip breathing (for shortness of breath)

Shortness of breath can be physically and emotionally anxiety-provoking and can affect your quality of life. This technique is one of the most helpful things you can do when you feel short of breath. The lip position helps keep the breathing tubes open and maintains better pressure in the air sacs in the lungs. It can reduce breathlessness, slow rapid breathing, help empty stale air out of the lungs, increase breathing volume and lengthen the exhale (which helps with anxiety). It also encourages the contraction of the abdominal muscles, moving the diaphragm up to empty the lungs more fully, allowing the fullest possible in-breath.

- **Breathe in slowly through your nose**, as though smelling something delicious. Relax your neck and shoulders as much as possible.
- Lean slightly forward and **softly, gently, s-l-o-w-l-y blow out through pursed lips**, as though cooling hot soup or using the breath to flicker a candle. Do not force the air out.
- Continue to do this for as long as needed.

5-4-3-2-1 (for deep relaxation)

This self-hypnosis technique can be used to relax in stressful situations, and to re-centre yourself. It can help with pain, sleeping, anxiety, scary thoughts and nightmares, and symptoms of post-traumatic stress. Do not use when driving, because it narrows peripheral vision.

- Find the most comfortable position you can and find something pleasant to focus your eyes on.
- Breathe normally. Your eyes can stay softly open unless you wish to close them or are using this to fall asleep. Keep your head and eyes quite still.
- Open your senses. Now name **out loud** (to deepen the effect): 5 things you see, 5 things you hear and 5 physical sensations you are aware of in your body. Notice each detail, maybe taking a breath between each one.
- Naming an item more than once or counting on your fingers is fine. If you lose count, simply begin again. If pain or discomfort is present, notice what needs to be noticed, then move on to notice other sensations.
- Now proceed to **4 sights, sounds and sensations**, and then to **3, 2 and 1 of each category**.
- Repeat the whole cycle as needed to deepen the effect.
- When you are finished, take 5 regular breaths to reorient yourself. To fall asleep, let your eyes close at any point.

For families and caregivers

Family member and caregiver self-assessment

This self-assessment tool is intended to help family members and caregivers identify aspects of their lives that are a concern or problem at the moment. If you feel overwhelmed or distressed doing this self-assessment, you may want to stop and come back to it at another time. Victoria Hospice counsellors are available to help you understand and work through whatever thoughts or feelings arise during or after completing this assessment.

Read each item and circle the number that best represents how much of a concern or problem this is **currently** in your life. You may want to complete this in one sitting or in several. You may also want to do the self-assessment more than once and notice how your answers change over time.

	Not a problem	A slight problem	A problem	A major problem	An overwhelming problem
1. Difficulty with memory or focusing my attention	1	2	3	4	5
2. Having enough information about the disease and how to provide care	1	2	3	4	5
3. Lack of understanding about palliative care services	1	2	3	4	5
4. Feeling isolated	1	2	3	4	5
5. Communication or conflict within the family	1	2	3	4	5
6. The safety of the patient	1	2	3	4	5
7. My own health	1	2	3	4	5
8. Asking others for help	1	2	3	4	5
9. Financial pressures	1	2	3	4	5
10. Having my spiritual needs met	1	2	3	4	5
11. Having opportunities to take breaks away from caregiving or from the home	1	2	3	4	5
12. Feeling that I won't be able to cope in the future	1	2	3	4	5
13. Feeling emotionally distant from the patient	1	2	3	4	5
14. Not feeling adequately supported by health care providers	1	2	3	4	5
15. Finding something to be grateful for at this time	1	2	3	4	5

Focus on family members and caregivers

Finding balance

A big challenge for family members is finding balance in caring for yourself in the midst of caring for another. You may have extra tasks and responsibilities at the moment. You are fulfilling your usual roles and chores plus those of the patient and adding on new tasks, such as organizing caregivers, picking up prescriptions, giving medications, driving to appointments, entertaining visitors and communicating with the care team. That's not to say that you don't have the interest, time or energy for pleasurable activities and moments. It may simply mean that you need to plan for or focus on these times more carefully. (See "Caregiver resilience: Strategies for self-care" later in this section.)

You may also find that you are overwhelmed at times by conflicting thoughts and feelings about this situation: you may feel great satisfaction in being able to care for the patient, yet at the same time feel resentment or anger about the demands being placed upon you. You are dealing with and grieving the many losses in your own life, as well as witnessing the losses experienced by the patient. You may feel physically and emotionally exhausted, wondering how much longer you can "do this." All of these reactions are to be expected.

And you worry that if you get sick or overly exhausted, you will not be able to give the kind of care that has become important to you. However, there may be help available from family and friends or from community services such as Victoria Hospice volunteers, home support agencies and various support programs. Talk to your Home and Community Care nurse or Victoria Hospice counsellor about available resources.

Reflection

How can you care for yourself while caring for another?

What three things would be most helpful to you at this time? Think about ways your family, friends or neighbours could support you (e.g., doing errands, practical chores or offering respite).

What would a mini-rest or break look like to you right now?

Planning for care

Uncertainty – not knowing what lies ahead – can be very unsettling or worrisome for families. You may have questions about practical things, such as hospital beds or wheelchairs, giving medications or making funeral arrangements. You may wonder how this particular disease will progress, “how long” your loved one may live, and what you can expect to see. You may wonder whether you are able to continue care at home, or whether you need to consider a bed at the Victoria Hospice Palliative Care In-patient Unit or other setting.

If you want to know about future care needs, funeral planning or financial and legal affairs,² contact your Home and Community Care nurse or Victoria Hospice counsellor. They can answer many of your questions and provide you with written information, or direct you to the appropriate resources.

Reflection

Think about what you are hoping for in the coming weeks and months.

What information would be most helpful to you at this time?

Are there things you will want to know in the future?

² Dial-A-Law (1-800-565-5297, www.dialalaw.org) and the Lawyer Referral Service (1-800-663-1919) offer information on a number of topics and can refer you to legal services if you do not have your own representative.

Communication

While your family may share many common characteristics, values and interests, each of you have unique ways of looking at and dealing with things. These differences may be appreciated and enjoyed, but they can also cause challenges when families are stressed. Dealing with the ongoing change, multiple losses and uncertainty of having someone seriously ill and dying in the family can heighten everyone's stress level. This makes it important to not only plan for self-care, but also to plan for family care. Family care starts with communication, and good communication requires time, honest discussion, respect and agreements about ways to make decisions.

While it may seem easier to deal with this situation on your own, to hide your thoughts and feelings, or to protect other family members from the worry or turmoil, this will likely not work well in the long run. When people are excluded or ill-informed, they often feel resentful and hurt, and it becomes harder to work together. Finding effective ways to communicate with one another at this time will help patient care and family relationships.

Sharing thoughts and feelings can ease one's sorrow and sense of being isolated and alone. However, for some this is not an easy conversation to have. It may help to talk first with a Victoria Hospice counsellor to plan such a conversation or to have the counsellor be present when you meet with your family, so that everyone's concerns and questions are addressed.

Involving others in tasks, information-sharing and decision-making can ease the burden and lead to more effective planning. Continuing to reminisce about the past, share pleasurable activities and discuss upcoming events can help to nurture and normalize family life.

Remember that family communication needs to include the patient!

Reflection

Consider the challenges you and your family have been facing.

Is there something important to talk to your family about (e.g., information, secrets, concerns)?

Is there an activity that your family would enjoy doing together?

Is there an upcoming decision that your family could help you with?

Feeling helpful

Sometimes family and friends wonder how to help someone who is ill. Remember, your relationships pre-date this illness and there may be activities or interests that you have shared over the years that you can continue or reminisce about now. There may be practical jobs or errands that need to be done, or it may be a time for quiet conversations and heartfelt presence. The following suggestions can help you find ways to be close and supportive:

- Touch – an embrace, gentle massage or a squeeze of the hand can be comforting and express your caring
- Humour – enjoying laughter together can bring lightness and pleasure
- Reminiscing – photos or stories are reminders of shared memories and life
- Silence – can be as comforting as conversation and require less energy
- Asking what's needed or wanted – allows the ill person to have more control
- Reading, singing, offering prayers and playing music may be pleasurable or comforting to the person and those who care for them

Caregiver resilience: Strategies for self-care

Taking good care of yourself at this time is both important and difficult. However, even small efforts can have great benefits. Consider incorporating a strategy from each of the following categories into every day. Maintaining your health will allow you to be more helpful – refreshed, renewed and restored.

Physical

- Eat properly with balanced, even if small, meals.
- Exercise (e.g., walk, swim, do yoga, do tai chi).
- Get adequate rest and sleep (e.g., put your feet up regularly).
- Consider massage, acupuncture or other complementary therapies.

Emotional

- Find ways to cope/deal with your grief and the thoughts and feelings that arise.
- Find quiet time to be alone (even five minutes is helpful).
- Plan some time away from care on a regular basis.
- Meet with a counsellor or a support group.

Social

- Meet with friends who understand what you're going through and can talk about shared interests.
- Try to stay connected with your favourite activities (e.g., golf, bridge, going for lunch).

Spiritual

- Stay connected; if you have a faith community, talk to your pastor, rabbi, priest or teacher.
- Spend time in a nurturing place (e.g., beach, sacred place, nature).
- Reflect on your beliefs and what is most important or meaningful to you now.
- Reaffirm life.

Thoughts

- Read a light or inspiring book.
- Listen to soothing music.
- Meditate, or use stress reduction exercises (see the relaxation techniques in "Patient resilience: Strategies for self-care")
- Write in a personal journal, paint or do collage.

Reflection

Consider creating a “self list” for yourself.

Activities I want to do more of

One thing I can do for myself every day

Three things am I grateful for in my life now

One thing I can ask someone to help me with

Question prompt list³

These questions may help you communicate and gather information from your palliative care providers. Your Home and Community Care nurse, or the Victoria Hospice Community Resource Coordinator (250-370-8714) will help answer your questions.

Patient concerns

Victoria Hospice palliative care services

- What can Victoria Hospice palliative care offer me?
- How do I access the services offered by Victoria Hospice?
- Who should I call after hours or in emergencies?
- For what reasons would I go to the Victoria Hospice Palliative Care In-Patient Unit?
- Are there costs involved in receiving these services?
- How will my family physician and other specialists remain involved in my care?
- Who will see me on a regular basis from now on?

Medications

- What are the side effects of any new medications that are prescribed for me?
- Will these new medications affect any of my current medications or other medical conditions?
- What is the cost of any new medication?
- Can I get these new medications from my local pharmacy?
- Who will renew my prescriptions if a palliative care physician is involved?
- How can I keep track of all these medications?

Financial/practical

- What financial assistance is available for my caregiver or me?
- Is there someone I can talk to about financial matters?
- Should I designate a Power of Attorney?
- What is a representation agreement and do I need one?
- Who might help me with preparing a will or arranging funeral plans?

³ Adapted from Clayton, Butow, Tattersall et al., Journal of Clinical Oncology. 2007;25(6):715-723.

A Guide to Physical Symptoms and Care

This section includes information sheets describing strategies that we have found might be helpful in various situations. Please feel free to remove any of the sheets from the binder to use as you wish. Each sheet also includes space for you to make your own notes.

Taking Medication

Some of us are reluctant to take medications except for those odd times when we have temporary minor pain or are fighting an infection. However, for some people medications provide a new lease on life by controlling symptoms that cause problems when they are left unattended. For example, people with heart conditions need their medications to regulate their hearts and diabetics require insulin to control their blood sugar so they can lead normal lives.

For people who have a life-threatening disease, medications may mean the difference between being uncomfortable and experiencing some quality of life. Like the diabetic needing insulin, the person with advanced disease often requires daily medications. These are prescribed by the doctor to relieve symptoms such as pain, nausea or shortness of breath.

Not everyone experiences the same symptoms to the same degree. If you need medication to relieve your symptoms, it helps to know something about how it works, how to take it and what to expect.

You will need to discuss your medication program with your family physician and Home and Community Care nurse and plan a schedule to follow. The Medication Record sheet included later in this section is intended to assist you in tracking your medication times. (Extra Medication Record sheets are included in Appendix A.) We have also included some general tips on scheduling and taking medications that we hope will help in your treatment.

Scheduling

Planning your medication schedule is easier if you use the Medication Record, which you can find at the end of this section. (You can find extra copies in Appendix A.)

Medications can be prepared ahead for future doses and kept in a dosette, which is a container that has separate sections for each medication time. A dosette can be purchased from any pharmacy.

Blister packs can be arranged for a week's supply of medications through your community pharmacy.

If you require a medication during the night, it is best to get it ready and place it on your bedside table. Set the alarm for the time to get up. You need only take the medication and then return to sleep.

Swallowing pills

If you have trouble swallowing pills, try some of these tips:

- Swallow water first to moisten your throat, place pills at the back of your tongue, and follow with more water. Try to relax your throat as you swallow. Tilt your head forward.
- Mix pills in applesauce, ice cream, sherbet or pudding – anything that has substance enough to carry the pills down your throat. Some pills can be crushed and then mixed.

Check first with your doctor or pharmacist about which ones can be crushed. Small pills can be put into a gelatin capsule, then swallowed together in one capsule instead of separately.

- If you have trouble with pills, check with your pharmacist to see if the medication comes in a liquid form and ask your family physician to change the prescription.
- If you are taking a liquid medication and have trouble with the taste, keep the bottle in the refrigerator or disguise the taste with another liquid like pop, juice or milk. Use different liquids so you won't become accustomed to a bad taste with any one drink.
- If you are still unable to swallow your medications, check with your family physician for alternative ways to take them, such as suppository or injection. It is important that your medication schedule not be interrupted to ensure that your comfort level is maintained.

Unexpected side effects

The medications prescribed for you are intended to make you feel better by controlling your symptoms. Each person reacts differently to medications, depending on their unique body chemistry.

Should you experience any **unexpected side effects** from the medications, or if they are not doing what you expect them to do, discuss your concerns with your family physician or Home and Community Care nurse as soon as possible. A slight adjustment in dosage or a change in the type of medication should return you to your previous level of comfort.

Notes

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Pain or Discomfort

You may experience a variety of sensations that you might describe as pain or discomfort. Pain usually begins at the physical level but is affected by your thoughts and emotions. We recommend that you talk to your family physician about the specific causes of your pain. It is important to remember that pain can be controlled in a variety of ways, and your care team will devise a plan to help relieve your discomfort.

You may notice:

- Your discomfort comes and goes.
- Certain things make it worse and certain things relieve it.
- Your pain varies in intensity (e.g., mild, moderate, severe).
- Your activity level decreases.
- Your ability to sleep is affected, so you don't get adequate rest.
- You don't feel like visiting with family and friends.
- You feel irritable or agitated.

Comfort measures

- Take pain medication on a regular basis, according to the schedule developed with your family physician or Home and Community Care nurse. A constant source of discomfort requires a constant source of relief.
- An extra half dose of pain medication can be taken between regular doses to provide an extra boost if pain is not completely relieved. This is called a "breakthrough dose."
- A warm blanket can soothe cramping pain.
- Find a new position to relieve the discomfort of stiffness.
- Gentle massage of your hands, feet or back may be soothing.
- Activities that provide diversion may help distract you from your pain include:
 - watching television
 - listening to music
 - having someone read to you (stories, poetry, prayers, etc.)
 - listening to a relaxation tape
 - practising a visualization exercise.

Other measures

It is important for you to tell others what you notice about your pain, so that treatment can be adapted to your particular needs.

If you are unable to take your pain medications regularly or find that they are not providing the relief they once did, or you are requiring many break-through doses to be comfortable, please contact your family physician or Home and Community Care nurse for advice.

Shortness of Breath

Problems with breathing can result from physical changes caused by the progression of the disease. We recommend that you talk with your family physician about the specific cause of your shortness of breath.

You may notice:

- You become breathless when you move around, get dressed or try to carry on a conversation.
- You have difficulty breathing, even when you are resting.
- Your breathing sounds congested.
- You sometimes cough up mucous.
- You feel the need to cough up mucous and find that you are unable to.
- You feel anxious or frightened if you are unable to breathe normally.

Comfort measures

- If your family physician has prescribed any medication for shortness of breath, take it as directed.
- If your shortness of breath is worse when you move, try to plan rest periods between your activities.
- If conversation makes you feel breathless, try reducing visiting times or ask family members and friends to just sit quietly with you so you do not feel the need to talk.
- You might find a humidifier helpful in loosening mucous so you can cough more easily.
- Get as much fresh air as possible, by opening a window or by using a fan blowing directly at your face.
- Remove any clothing or bedding that makes you feel constricted.
- Change your position if possible. Usually a high sitting position is best. This can be done by putting several pillows behind your back and resting your arms on pillows.
- You might find a recliner chair useful for sleeping, as it keeps you in a semi-upright position.
- Ask a family member or friend to remain with you if you feel anxious.
- Try to stay as relaxed as possible; tensing your muscles will add to your feeling of breathlessness.

Other measures

If prescribed medication and comfort measures do not relieve your breathlessness, please call your family physician or Home and Community Care nurse.

Nausea and Vomiting

Nausea and vomiting are common symptoms in a progressive disease. There are several possible causes for nausea and vomiting, including irritation or pressure on part of the digestive system, eating when you feel full or aren't hungry, and side effects from medications. We recommend that you discuss the specific cause of your nausea and vomiting with your family physician.

You may notice:

- You feel sick and are unable to eat.
- You vomit occasionally or frequently.
- You are unable to keep down oral medications.
- You are comfortable at rest but feel ill or become nauseated with any movement.

Comfort measures

- Adjust your diet according to the severity of your nausea and vomiting. For example, very small amounts of clear fluids are best for severe vomiting. Seek advice regarding your particular situation from your family physician or Home and Community Care nurse.
- Take prescribed anti-nausea medications regularly, as directed. It can often help to take these medications 30 minutes before you take any other medications.
- While you are feeling nauseated, it may be necessary to take medications in a way other than by mouth. Your Home and Community Care nurse may suggest suppositories or injections while you are feeling sick. It is important to maintain your medications to ensure your comfort through this temporary situation.
- Freshen your mouth thoroughly after vomiting with a mild mouthwash or toothpaste. Stomach contents can be very irritating to the lining of the mouth.

Other measures

If you are unable to tolerate oral medications, it is important that you contact your Home and Community Care nurse or family physician.

Poor Appetite

You may notice that you no longer desire the same amount or type of food that you once did. As you become less active, your body will naturally not want or need as much food. It is important to remember that this is a normal and expected change. Do not force yourself to eat, as this is likely to make you feel uncomfortable.

You may notice

- You eat very little.
- You feel nauseated if presented with large portions of food.
- You do not desire solids and find that liquids are filling and satisfying.
- You are losing weight.

Comfort measures

- Have nourishing snacks (e.g., eggnog, soups, ice cream).
- Keep meals small and light. Take favourite foods that are soft and easy to eat.
- Ask a family member or friend to sit with you while you eat if you are unable to be with the rest of your family at mealtime.
- Make sure you are in a comfortable position before starting to eat.
- If nausea is a problem, tell your Home and Community Care nurse or family physician, so appropriate medication can be ordered.
- Keep your mouth fresh and clean.
- If you dentures have become loose, get them relined or try Polygrip.
- If your lack of desire for food is upsetting to family members or caregivers, ask your Home and Community Care nurse or family physician to discuss this with them.

Notes

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Dry, Sore Mouth

Your mouth may become dry and sore if you are unable to drink your usual amounts of fluids. This may happen if you have nausea, vomiting or a lack of appetite. The reduced amount of body fluid will also dry up saliva. A dry mouth can also be aggravated if you tend to breathe through your mouth.

You may notice:

- Your mouth feels dry and uncomfortable.
- Your tongue is red and coated.
- Your lips are dry and cracked.
- You have a bad taste in your mouth.

Comfort measures

- Clean your mouth frequently, especially after eating.
- Check commercial mouthwashes before you use them, as many contain alcohol which makes the dryness worse. Sometimes rinsing with other solutions may be helpful. For example, try:
 - a combination of 4 cups water, 1 teaspoon salt, 1 teaspoon baking soda
 - diluted brandy or your favourite alcohol
 - ginger ale
 - a combination of 1/3 water, 1/3 hydrogen peroxide, 1/3 mouthwash.
- If you have dentures, remove them and brush twice a day.
- After cleansing your mouth, put a water-soluble lubricant such as Muco or K-Y Jelly on your lips.
- Take small amounts of fluids as often as possible. Sips of water or diluted juices are best if nausea and vomiting are a problem.
- Suck on ice chips, popsicles or fresh pineapple chunks.
- Try a commercial product called Moi-Stir to moisten your mouth. This comes in a swab or spray form and is available over the counter at your pharmacy.
- Add small amounts of lemon juice to ice water or crushed ice to stimulate saliva production.
- Use a small spray or spritzer bottle to mist your mouth with water.

Thrush

Thrush sometimes occurs in the mouth because of the body's lowered resistance to infection.

You may notice:

- Patches of white curds on your tongue or inside your cheeks.
- You have a sore throat or a burning sensation in upper chest.
- You have difficulty swallowing.
- Your tongue is swollen and reddened.

Comfort measures

- Your family physician can prescribe medication to relieve thrush.
- Clean your mouth after eating with a very diluted mouthwash or plain water to reduce any stinging.
- Gently remove white patches when they begin to loosen, using a soft toothbrush.
- If you have dentures, soak them overnight in full-strength Listerine. Rinse before putting in your mouth.

Notes

Constipation

Constipation is a common problem. It can be caused by progression of the disease, changes in your diet and/or decreased activity. Also, some pain medications slow the movement of the bowel.

It is important **not** to cut back on pain medications if you are constipated. There are bowel medications that can be given to counteract the slowing effect of these medications.

You may notice:

- You have bowel movements less regularly and sometimes not for several days at a time.
- Your stool is hard and you need to strain to have a bowel movement.

Comfort measures

- Take bowel medications as advised by your family physician or Home and Community Care nurse.
- If nausea is not a problem, take fruit juices, fluids of any kind and natural laxative foods.
- If you have no bowel movement for three days, it is important to tell your family physician or Home and Community Care nurse so your bowel medications can be adjusted. There may be times when you will need a suppository or a small enema.

Notes

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Skin Breakdown

Sore areas or breaks in the skin can occur if you have lost weight and are in bed for long periods of time.

You may notice:

- You have red, sore skin at pressure areas such as your tailbone, elbows, and so on, or in skin folds.
- You have itchy skin.
- You have rashes or broken skin areas.

Comfort measures

- Change your position frequently, at least every four hours.
- Lift your body across the sheet rather than sliding.
- Use small pillows or padding, such as rolled-up towels, to keep skin surfaces from rubbing together and to keep skin from constant contact with the bedding.
- Have extra padding put on your bed. Foam mattresses, sheepskin pads and other special mattresses are available.
- A full bath is not required daily, as frequent washing can dry the skin. Keep skin folds and creases clean and dry.
- Use lotions or oils in the bath to help dry or itchy skin.
- If you notice any reddened or open areas, tell your Home and Community Care nurse . There are protective dressings that can be applied to sensitive skin or pressure areas to reduce irritation and make you more comfortable.

Notes

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Forms

This section contains four forms:

- **Instructions for Care** provides space for medical professionals to write down any care instructions for patients, family and caregivers.
- The **Medication Record** and the **Symptom Monitor Chart** will help you keep track of medications and symptoms.
- You can use the **Patient, Family and Caregiver Journal** in any way that you find helpful.

Extra copies of each of the **Medication Record** forms are provided in Appendix A.

<div>Palliative Care Home Medication Record</div>		Patient Name: _____																										
		Night				Morning				Afternoon				Evening														
Medication	Date	Time →	am	1	2	3	4	5	6	7	8	9	10	11	12	pm	1	2	3	4	5	6	7	8	9	10	11	12
Medication	Date	Time →	am	1	2	3	4	5	6	7	8	9	10	11	12	pm	1	2	3	4	5	6	7	8	9	10	11	12
Medication	Date	Time →	am	1	2	3	4	5	6	7	8	9	10	11	12	pm	1	2	3	4	5	6	7	8	9	10	11	12
Medication	Date	Time →	am	1	2	3	4	5	6	7	8	9	10	11	12	pm	1	2	3	4	5	6	7	8	9	10	11	12
Medication	Date	Time →	am	1	2	3	4	5	6	7	8	9	10	11	12	pm	1	2	3	4	5	6	7	8	9	10	11	12

Symptom Monitor Chart

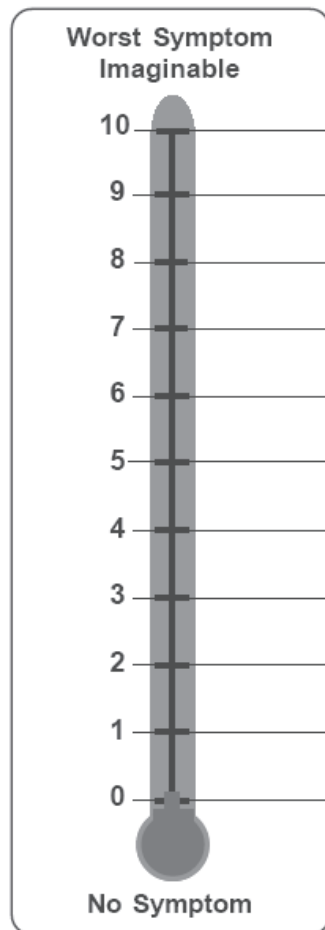
To Use: Rate the symptom on a scale of 0-10 using the adjacent Symptometer for reference. Mark the number with an "X" on the table below. Then, join the "X"s by drawing a line to see if the symptom is getting better or not.

This should be done twice daily:

AM	10:00 am (approx.)
PM	6:00 pm (approx.)

Symptom Being Assessed:

Date →



Symptometer
© Victoria Hospice Society

Note: For accuracy, the number "10" means the 'worst pain imaginable.' That is, a "10" should only be used if the patient is visually in extreme distress and literally screaming out in pain. It does not mean that the pain is simply "bad."

Also, the number "0" should be used only if there is absolutely no pain. An "dull ache" is not "0."

Assessed By: P = Patient
F = Family
N = Nurse
D = Doctor

Mark the letter of the Assessor in the box above each time the symptom is assessed. If the **patient is able** to indicate the level of pain or other symptom, then use the letter "P". If the **patient is unable** to indicate due to weakness, confusion or coma, then the family or Home Care Nurse marks the level of "observed pain."

Patient, Family and Caregiver Journal

Use this sheet in any way that is helpful: to keep notes about events, list questions to ask the family physician or Home and Community Care nurse, record thoughts and feelings, write poetry, draw, and so on. It can be left in the binder, or removed for keeping.

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4. Death at Home – For Family and Caregivers

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Preparing for Death: A Guide for Family and Caregivers

As a person is dying, his or her body will go through a number of physical changes as it slows down and moves toward the final stages of life. Many of these changes are normal and to be expected. Please remember that each person is different; all of these signs and symptoms won't occur for everyone. Although the following changes are presented in the order in which they usually appear, some variation is common.

When you notice changes or have any questions or concerns, please talk to your family physician, the Home and Community Care nurse, or Victoria Hospice. They can make any needed adjustments and offer practical suggestions.

We hope that this information will help you prepare for the changes that are likely to happen. We have also included some practical advice and comfort measures to help you in your role as caregiver and advocate.

A dying person may...

Have decreasing strength

This usually occurs gradually over weeks and months, but can also happen fairly quickly over a matter of days. As the person becomes weaker, you may need equipment in the home, such as a walker or commode, to help with safe and easier care.

Suggestions:

- Have your Home and Community Care nurse or physiotherapist assist with arranging equipment in the home.
- Reassure the patient. Loss of independence may be upsetting and one more thing to grieve.
- Consider using a call bell or intercom.
- Space activities and provide for periods of rest.

Sleep longer

A dying person may sleep for longer periods and sometimes have difficulty waking. Times of increased activity and communication may be followed by hours or days of deep sleep and unresponsiveness. In the moments before death occurs, many people appear to be sleeping or comatose.

Suggestions:

- Plan visits for times when the person is more wakeful and alert.
- Encourage visitors to sit quietly at the bedside. Physical touch, such as holding hands, may be a good way to connect.
- Avoid over-tiring the person. Limit the number and length of visits.
- Assume that the person can hear everything on some level.

Have decreased appetite

This is a normal response for seriously ill people. They feel less hungry and thirsty because they are less active and their bodies are unable to process intake in a normal way. If they are encouraged to eat and drink more than they want, this can sometimes lead to problems like nausea and vomiting. It is difficult to watch those you care for eat less than usual. However, it is wise to offer small portions and encourage them to eat and drink only as much as they want.

Suggestions:

- Ask the person what he or she wishes to eat or drink.
- Serve small, nourishing servings of eggnog, soups, ice cream, and so on.
- Make mealtime a social occasion.
- Do mouth care before and after eating.

Emotional and spiritual changes

A dying person may talk about going on a trip, ask to go home, or speak to people you don't see. Strong emotions such as fear or anger may also be expressed near end of life. Although not everyone will experience these responses, they are considered normal and expected.

Suggestions:

- Continue to respond in your usual way.
- Realize that the dying person may be working through important issues, such as life review, saying goodbye and letting go.
- Accept that unusual or symbolic language or references are not always signs of a problem and may hold helpful insights into the dying person's experience. This is explained in a book called *Final Gifts* (1993) by Maggie Callanan and Patricia Kelley, which may be available on loan from Victoria Hospice.

Become confused and/or restless

A dying person may be unable to recognize familiar people or surroundings, see things that you cannot see, pull at his or her sheets and clothing or reach into the air.

Suggestions:

- Speak calmly, slowly and in a manner that is familiar to the person.
- Offer reassurance about the person's safety and your presence.
- Consider playing calm and soothing music, gently placing your hand on the person or offering a gentle hand or foot massage.
- Do not argue if the person's reality is different. Sometimes going along with someone who seems mildly confused allows the situation to pass.
- Keep the atmosphere quiet and turn down the lights. Try to minimize stimulation.

- Give gentle reminders about the time, where the person is and who is present in the room.
- Medications are helpful when confusion and or restlessness are ongoing or escalating.

Have difficulty swallowing

A dying person may forget to swallow or have difficulty swallowing as weakness increases. Foods and fluids with the consistency of yogurt are easier to swallow than thin, water-like fluids. As the person's condition declines, he or she will lose the mechanical ability to swallow and will be unable to have any oral intake in the last few days of life.

Suggestions:

- Give only small amounts of food and fluid.
- Remind the person to swallow.
- If patient chokes or coughs consistently with attempts to swallow, have your Home and Community Care nurse assess the situation. Medications may need to be given in alternative ways.

Have irregular or shallow breathing

A variety of changes can happen with breathing. Commonly, there may be pauses between breaths of 10, 30 or 50 seconds or longer. Changing breathing patterns are normal, and usually the dying person is unaware of and untroubled by these changes. There is nothing to do about these changes except note that they are another signal that the person's condition is changing.

Suggestion:

- Remind yourself to breathe. Sometimes caregivers temporarily forget to breathe when focused on the dying person's breathing patterns.

Develop wet-sounding breathing or moaning

As the body weakens, saliva may collect at the back of the throat and cause wet-sounding breathing. This wet sound may also be caused by congestion deeper in the lungs. Moaning as the person breathes in or out may or may not be an indication of discomfort.

Suggestions:

- Discuss what you are hearing with the family physician or Home and Community Care nurse. There are medications that can decrease congestion and/or provide relief if pain is a concern.
- Change the person's position. Sometimes turning him or her to one side, raising the head of the bed or using pillows to prop the person up can be helpful.

Become unresponsive

The person may no longer respond to voice or touch or may seem to be sleeping with his or her eyes open.

Suggestions:

- Continue to speak to the person. Your familiar voice is likely to be comforting. It is generally believed that people can still hear, even when they cannot respond verbally.
- Tell the person what you are going to do before you do it (e.g., a position change, personal care or giving medications).
- Let the person know when you are entering or leaving the room.

Lose control of bladder or bowels

Loss of bladder and bowel control is normal at the end of life.

Suggestions:

- Protective padding for the bed is generally required.
- A catheter may be helpful.
- For a person who is bedbound, use protective briefs with taped side openings, which are easier to use than pull-up briefs.

Have a change in body temperature

The person may feel unusually warm or cool to the touch. When the temperature-regulating part of the brain is not working as well, the person may initially feel warm to touch. Then, as circulation decreases, the body protects the core organs. As a consequence, the person's arms, legs, hands and feet may feel cool to touch and may look somewhat bluish in colour. This is a normal part of the dying process and generally signifies that death will be within hours.

Suggestions:

- Remove blankets or place cool cloths on the person's forehead if he or she feels too warm.
- Add a blanket and/or keep the arms and hands covered if the person feels cool.

What about you? Suggestions for the caregiver

At this time, you may find you are so busy being a caregiver that you are not looking after your own health. Remember, it can be difficult to care for another when you don't care for yourself.

Self-care suggestions

- Ask for and accept help with care, household and other tasks (e.g., phone calls, shopping).
- Find ways to handle updates and inquiries (e.g., use email, designate one person).

- Notice what gives you comfort or pleasure (e.g., time with others, reading, being in nature).
- Remember to breathe, to eat and to sleep.
- Set limits and say no when you need to. Let others know how you are doing.
- Don't ignore the humour and beauty in life.
- Share stories and memories.
- Acknowledge that this is a difficult time. Remember that everyone (including you) is doing their best.
- Do anything that feels like self-care (e.g., massage, haircut, nap, walk, sit quietly, cry).
- Maintain your spiritual and religious practices.
- Sing, play or listen to music that comforts or uplifts you.

Saying goodbye

For many people, saying goodbye is very important. The person who is dying, as well as friends and family members, may wish to express their love, gratitude and sorrow to each other. Some people may say goodbye through conversations, letters, trips and rituals, or simply by being together. Some dying people are most comfortable with having people around, while others are more at ease with quiet and privacy. Sometimes a person seems to choose the time to die, perhaps when alone or when particular people are present.

You may wish to:

- Talk about shared experiences, offering and receiving love.
- Offer or ask for forgiveness.
- Remember that tears are a natural and healing release of sadness.
- Reassure the dying person that you and your family will be okay.
- Choose a funeral home if you have not already done so.

As Death Approaches

Note: Please feel free to remove this information sheet from the binder to use as you wish.

Changes at this stage will vary from person to person. They are usually more difficult for you to watch than for the patient to experience. You may feel anxious, and may want a specific answer about how soon death is likely to occur. Precise predictions are often difficult, but you can expect that time will be limited once oral intake is not possible, urine output stops, and there are obvious changes in breathing patterns. The more you understand about what might happen and what you can do about it, the more you will feel able to handle the situation.

You may notice that the person:

- is extremely weak
- has difficulty swallowing fluids and medications
- slips into a coma, which is a sleep-like state, and is unable to respond verbally
- has decreased urinary control and output
- has irregular breathing with periods when breathing stops for 10–30 seconds
- has moist or rattling breathing sounds
- has cool hands and feet, which may also appear mottled or patchy in colour

Comfort measures

- Turn and position the person at least every four hours. Your Home and Community Care nurse can instruct you on different moving and positioning techniques.
- If the person is unable to swallow, do not attempt to give fluids – this may cause choking. Rather, a gentle mist of water may provide comfort for a dry mouth.
- Continue to give pain medications as scheduled until death. If the person is unable to swallow, these medications will need to be given by another method. Contact your family physician, Home and Community Care nurse or Victoria Hospice if oral medications are becoming difficult.
- Moisten the mouth with a wet cloth or mouth swabs (e.g., Moi-Stir) and lubricate lips with ointment.
- Place protective pads or towelling under the patient's hips, and change when necessary.
- If the breathing sounds moist or “rattling,” contact your family physician, Home and Community Care nurse or Victoria Hospice to find out whether medication that may ease this is available.
- Use bed coverings as usual.
- Continue talking and touching to let the person know you are there.

At the Time of Death

No matter how much we prepare, no matter what we expect, the moment of death will arrive in its own time and in its own way. The experience of dying is different for every person.

You will notice that the person's:

- breathing and heartbeat have stopped
- eyes are not moving and may be open or closed
- mouth may fall and remain open as the jaw relaxes
- skin becomes pale and waxy looking.

There may be no response.

Do what you feel will be helpful. For example:

- Allow your tears and feelings to come.
- Breathe deeply.
- Be in physical contact with others: hug, hold hands.
- Gather around the bed to say a prayer or blessing, silently or together.
- Have a warm drink.
- Take the time you need.
- Do whatever feels right for you.

When death has occurred at home

- For an expected, planned death at home, do **not** call 911, police, ambulance or coroner.
- **Do** call the family physician, Home and Community Care nurse or Victoria Hospice. They will arrange for a nurse or doctor to come to your home to pronounce the death, unless you have chosen to waive a visit for pronouncement, and your family physician has completed a "Notification of Expected Death" form. (See "Pronouncement plan" in 2. Planning Ahead – For Patients, Family and Caregivers.)
- **Do** call family members, friends or your spiritual advisor if you would like someone to be with you.
- Spend as much time with the person who has died as you wish. Remember, there is no need to rush. Take time to absorb the reality of death and to say goodbye.
- After the nurse or family physician has pronounced the death, the funeral home can be called whenever you are ready. If you have not chosen a funeral home, do so at this time. (See "Funeral facilities" in 2. Planning Ahead – For Patients, Family and Caregivers.) It generally takes funeral home attendants about an hour to come, although this can vary greatly.

After the Death

This final leave-taking can be difficult. You may wish to spend time with the body of the person who has died, reminiscing and saying goodbye. Before the funeral home attendants arrive, you may want to bathe and/or dress the person or gather special objects or notes to send with him or her. You may prefer to choose the clothes you want the person to wear and give them to the attendants, or you can bring them with you to your meeting at the funeral home.

When the funeral home attendants arrive, they will move the body to a stretcher in preparation for leaving. The body will be placed in a special zippered bag made for the purpose of transport. Consider whether or not you wish to be present when the person's body is removed. You may wish to remain with the body or you may want to leave, go into another room or go for a walk while the stretcher is taken out.

Memorial or funeral plans can be made or confirmed during an appointment with the funeral home the next day. You will need to take a completed copy of the Information for the Vital Statistics Agency sheet (on the next page) to the appointment.

When the *Palliative Care at Home* binder is removed from your home or when you leave the Palliative Care In-Patient Unit, you will be given information about **Victoria Hospice Bereavement Services**. For more information, you can call the Victoria Hospice Bereavement Services office directly at 250-370-8868 (Monday through Friday, except holidays) or visit www.victoriahospice.org. (Also see 5. Bereavement – For Family and Caregivers.)

Information for the Vital Statistics Agency

You will need to provide the funeral director with the following information about the person who has died. The funeral director will forward this information, along with the medical certification of death, to the Vital Statistics Agency, Ministry of Health, in order to register the death. The funeral director can then issue a death certificate and a burial permit. (For more information, go to www.vs.gov.bc.ca/death.)

Name _____
LAST NAME ALL GIVEN NAMES IN FULL

Address _____
HOUSE/APT. NUMBER STREET/ROAD CITY/TOWN POSTAL CODE

Maiden name _____ Occupation _____

Birthdate _____ Age _____
MONTH/DAY/YEAR

Birthplace _____
CITY/PLACE PROVINCE/COUNTRY IF FIRST NATIONS, PLEASE GIVE BAND

Sex _____ Height _____ Weight _____ Religion _____

Date of death _____ Place of death _____

Marital status _____
SINGLE/MARRIED/WIDOWED/DIVORCED

Full name of spouse (if married/widowed/divorced) _____

Father's name _____ Father's birthplace _____

Mother's name _____ Mother's maiden name _____

Mother's birthplace _____

Next of kin _____
NAME

ADDRESS CITY/TOWN POSTAL CODE

BC Care Card Number _____ Social Insurance Number _____

Family physician _____
NAME

ADDRESS CITY/TOWN POSTAL CODE

5. Bereavement – For Family and Caregivers

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Bereavement

When someone important to you dies, your life changes forever. Bereavement can be a time of uncertainty, when it is hard to know what to expect or what is “normal.” The information in this section is intended to let you know about what may happen as you grieve and what you may find helpful.

Everyone’s grief is different

Family members and friends may respond in very different ways, and can be surprised by how they feel and act when death finally comes. Sometimes a person’s reactions can seem strange and unpredictable compared to how you know the person in other situations. You too may experience feelings that you don’t expect. All of this can be very unsettling.

A bereaved person may cry, sob, weep, wail or be silent. However, each person expresses grief in his or her own way. Some people experience a sense of relief now that the stresses and intensity of caregiving are over and the person who has died is at peace or no longer suffering. Other people may appear not to be expressing their grief at all, or may find comfort in keeping busy or taking responsibility for the many details and practical matters that need attention after a death. Some family members may feel panicky about being alone or out in public. Others may seem to be in a fog, or be forgetful and disoriented.

It is important to give each person time, as well as permission to experience grief in ways that feel right to him or her. This can be difficult for families when everyone is suffering or grieving, but not necessarily in the same way. Patience, negotiation and compromise may be required.

The early days of grief

The time immediately after a death is often full of activity, as friends and family gather for the funeral or memorial service and to offer each other support. This can be a time of sharing, when people acknowledge the life and death of someone close. There can be a deep and heavy feeling of sadness as people begin to feel the weight and emptiness of this loss.

Most often, the loving presence of family and friends provides comfort. However, while people can be drawn together by mutual sadness, they can also be pulled apart by conflicting needs and responses. Fatigue and grief can make you raw and vulnerable. It is important to be patient with yourself and others.

As time goes by

In the weeks after the death, routines may begin to reassert themselves. You may be trying to balance the ordinary demands of life with the changes and adjustments brought by the death.

There are likely to be some times when things go fairly well, and other times when things may be harder than you expected. This is a good time to check in with your family physician, and to look after your own health by eating well, exercising regularly and getting plenty of sleep and rest.

You may notice a shift in your grief, or you may feel unable to face your usual responsibilities. You may find that your thoughts, feelings and needs change from one week to the next. There may also be times when you feel stuck in the same place. You may have questions about what is normal or how to cope.

Just as you will grieve in your own way, you will also grieve in your own time. While you may get well-intended advice from others, it's important to listen to your own heart.

While you are grieving

Here are some things that we have learned from grieving people:

1. Grief is a natural part of the human experience, affecting all areas of our lives.
2. Even healthy, strong people may need support for their grief.
3. Each person grieves in his or her own way and time.
4. Asking for help isn't a sign of weakness, but it isn't easy either. Many people struggle with feeling more vulnerable than usual.
5. Bereaved people are experts on their own grief.

Visit www.victoriahospice.org to find out more. There are booklets and pamphlets on grief that you can download at no cost, as well as recommended reading lists and links to other resources.

Victoria Hospice Society Bereavement Services

The Victoria Hospice Society offers bereavement support for individuals and families, including children and teens, from volunteers and counsellors. Our services include telephone support; counselling; a variety of bereavement support groups, including drop-in and walking groups; education; and referrals.

For information about bereavement services, you can contact us Monday through Friday (excluding holidays) at 250-519-3040 or email www.hospice.bereavement@viha.ca, or in person at 102-4450 Chatterton Way, Victoria, BC V8X 5J2.



Appendix B: Victoria Hospice



Victoria Hospice is a registered charity that has, since 1980, provided end-of-life care focused on palliative treatment. Our nurses, counsellors, spiritual caregivers, physicians and trained volunteers provide comfort for the patient and support for the family, rather than a cure for progressive and life-limiting illness.

Care is offered in patients' homes, within our 17-bed in-patient unit, and as specific medical consultation to patients in other health care facilities. Over 300 trained volunteers provide companionship and support. Victoria Hospice offers bereavement support to families for up to one year after a death.

Roughly 50% of Victoria Hospice's annual operating costs are *not* covered by our health care system, and must be funded through community donations to our Victoria Hospice and Palliative Care Foundation.

Victoria Hospice also acknowledges the financial support of the Province of British Columbia.

For more information about Victoria Hospice, please visit our website (www.victoriahospice.org) or contact us directly:

Victoria Hospice Society

3rd Floor, Richmond Pavilion
1952 Bay Street
Victoria, BC V8R 1J8
General enquiries (24 hours): 250-370-8715

Victoria Hospice and Palliative Care Foundation

4th Floor, Richmond Pavilion
1952 Bay Street
Victoria, BC V8R 1J8
General enquiries: 250-519-1744