



Family Caregivers of British Columbia

Victoria Hospice – Palliative Care, Anticipatory Grief

At some time, in some way, we must all face the end of life. Most of us share a common hope that when death comes to us or to a loved one, it will be peaceful and free from pain. We hope to face death surrounded by those we love, feeling safe, comfortable and cared for. But most of us also share worries about whether that will be possible.

The thought of facing a life-threatening illness raises difficult questions. Here in Victoria, in the Capital Health Region, we are fortunate to have available one of the premiere hospice palliative care services in Canada.

Victoria Hospice Society (VHS) was founded in 1980 as a Ministry of Health pilot project. After two years and an in-depth assessment, permanent status was granted. VHS was fortunate to have the support of an earlier, community-based volunteer program called the Victoria Association for Care of the Dying (VACD). In 1983, VACD was incorporated into VHS as its volunteer component.

Throughout its history, VHS has worked closely with family physicians, home care nurses and other care providers to create a seamless program of care. Hospice palliative care provides physical, psychological, social, spiritual and practical support to people with life-threatening illness, and to their loved ones. It brings physicians, nurses, other health professionals, spiritual care workers, counsellors, volunteers, friends and family members together as a caring team, so patients can live their remaining time in comfort and dignity, surrounded by people who love them. Hospice palliative care is a flexible program of resources that are made available when and if they are needed and desired by patient and family. Professional standards of practice are being created in the field on a national level, so that all persons needing this support can feel confident of its quality.

One of the key questions that people ask is whether they can stay at home. Victoria Hospice and its allies on the Palliative Response Team have created many supportive services that can allow a person to remain at home with confidence. The Palliative Response Team is a key element – highly trained nurses and counsellors are available 24 hours per day to visit the home and help assess and treat any physical or emotional issues. With cell phone connections to the on-call Hospice physicians, any new medical orders that are needed can be obtained without delay. At any given time, over 85% of registered VHS patients are at home.

Sometimes an intense period of assessment is needed, when symptoms are complex and hard to manage. Victoria Hospice Society provides an inpatient unit with assessment beds for this purpose. In addition, it has nine Long Term palliative beds for those who cannot be cared for at home. Finally, one respite bed allows for a period of residence to give both patient and family a break from the high demands of caregiving.

Planning is a key element of hospice palliative care. In order to make good decisions, patients and family members need to have good information and be involved in discussions with the care team so that appropriate options are developed. Victoria Hospice Society provides each registered patient with a resource book, “Hospice Palliative Care at Home” which contains program and planning information, a professional section for charting and record keeping and many other resources.

Victoria Hospice depends on the community for almost 40% of its funding as well as for a significant portion of its staff – via the volunteer component. Our community response to VHS, in gifts of money and time, allow it to meet the heavy demands of our populations. Over 500 volunteers complete an intensive training program and work on the inpatient unit, in the community as companions and supporters and in the bereavement area.

Bereavement support is an important part of hospice palliative care – the program maintains contact and service to bereaved families for at least a year.

Victoria Hospice Society can be reached at (250) 370-8715. Staff is always available to provide further information.

By Jerry Rothstein

Anticipatory Grief: Family Caregiver's Constant Companion

When someone close to you is diagnosed with a terminal illness, everyone begins to grieve. This anticipatory grief process can be confusing and difficult. On the one hand you are attending to the needs of the family member who is ill and maintaining your relationship; on the other hand, you have begun grieving their loss and may be over-whelmed at times with complex feelings of sadness and loss. You may also wonder and worry about what will happen, how life will continue after the person dies. There is never enough time or energy to attend to these intense needs. The steps you take to cope are called tasks. You will find that you are engaged in all of these tasks at varying degrees at the same time. Looking at each of these separately will help you to understand more exactly the demands of the situation and to make the best use of family time, energy, and your ability to cope with the tasks.

1. Fluctuating from denial to acceptance of the illness and death

Some denial of reality is healthy and necessary for you to function. It allows you to take in information at a more tolerable pace, and gives you a break from the emotional stress of a situation. Acceptance of what is happening will not necessarily bring peace.

2. Establishing a relationship with health professionals

You may need to learn how to be assertive, in a constructive manner, as well as finding ways to deal with frustration. Family conferences with hospice team members can help to reduce your anxiety by opening lines of communications and giving you direct information. It may help to write your concerns down before meeting with hospice team members.

3. Meeting the needs of the dying person

As the illness progresses the patient's physical and emotional needs will change. Your task will be to help in the best way you can without taking away the patient's control or independence. Remember to ask about the patients' needs and wants. Discussion can make all the difference.

4. Maintaining the family

Everyone in the family takes on new roles and responsibilities when a family member is ill. At the same time, maintaining some of the family's normal routines is very important. This helps to give everyone some security in the midst of stress and change.

5. Living with emotions

During this time both patient and family experience intense swings in emotion. Having information about these feelings and being aware of your own reactions will help you begin to cope. It is important to let each other know how you are feeling and what you need. There may also be things that you prefer to discuss with someone outside the family.

6. Dealing with people outside the family

You have little energy at this time for outside relationships and everyone's reactions are unpredictable. Friends may avoid the sick person. You may resent others' stability and good fortune. People don't understand what you are going through.

7. Anticipating the family's new reality

It is impossible to imagine the future. However, estate planning, dealing with different kinds of unfinished business and building in emotional supports are things that can help you to prepare. You may need help with some of this.

8. Finding appropriate hope

What you hope for throughout this time will change. Long term plans need to be replaced by short term plans; you find yourself giving up treatment that aims for cure in favour of that which relieves symptoms and creates comfort. As you are able to accept the goal of comfort rather than cure, you are taking a step towards acceptance.

9. Making decisions

There may come a time when a patient is unable to make decisions. Prior discussions, the use of a Living Will or your knowledge of the person's wishes will help to represent their best interests.

10. Taking care of yourselves

When you are focused on caring for another it is hard to have energy for yourself and to see this as important. Building in time for self-care is crucial. Recognize that you have needs – physically, emotionally and spiritually.

These tasks are part of a process. You will find that you are more aware of different ones at different times. There is no set procedure or need for completions. The important thing is to do the best you can.

By Victoria Hospice Society

What is Hospice Palliative Care?

"Hospice palliative care" is the term now used to describe the holistic, interdisciplinary approach to the needs of dying persons and their families. In order to deliver such care, sensitivity to the expectations and needs of each patient and family member is essential. This may refer to ethnic and cultural differences in the approach to illness, dying and bereavement. It will always involve us in considering the right that each person has to make the choices for their care that meet their own values and needs. This also implies that we provide honest and clear information, for without good information it is difficult if not impossible to make good choices.

In hospice palliative care there is also recognition of the wide range of possible needs that patients and family members have. We have a corresponding requirement for our programs to provide a wide range of resources available to meet those needs. Along with such resources, we add the notion of "seamless" care. This means that our hospice palliative care programs and services are available in all settings where care might be needed – in the home; in the hospice palliative care unit, the acute care hospital, or long-term care facility. The need for communication and co-ordination is clear. Hospice palliative

care programs take responsibility for assuring each patient and family that the resources and services they need will be available. They are always provided by a team working from the same values and the same principles. Helping someone come to an appropriate death can be a challenging task for the family and professional care providers. It is not enough to view the person as the object of medical interventions (curative mode) or of a chronic illness care regime (extended care). Instead, care providers must relate to persons who are ill as whole persons. The process of dying is out of our control, and this obliges care providers to live with the rhythm of the person's life. Death will come when it will; meanwhile, the care providers need to remain open to the context of and developments in the dying person's life.

At the heart of hospice palliative care is our understanding that comfort is a necessary condition for quality of life. The well being of both patients and family members is of major concern to hospice palliative care programs. We know that physical symptoms such as pain or shortness of breath will inevitably dominate any person's awareness, the way a sore tooth pulls our attention to it. The field of palliative medicine that is part of hospice palliative care has made great progress over the past twenty-five years. We have learned how to manage even extremely difficult symptoms, so that the patient has a chance at both comfort and a clear head. This process takes work, trial and error and close monitoring, but the results are worth it.

If we stopped at the management of physical symptoms we would be doing our patients and families a disservice. Emotional, social, and spiritual issues come to the fore as well, when the issue is one of life and death. So the hospice palliative care movement has insisted on offering resources of counselling, companionship, spiritual guidance and support as necessary aspects of care. Highly trained volunteers play a significant role in these resources.

Hospice palliative care seeks to acknowledge and honour the special needs of people living with or dying from advanced illness. The major goal is comfort (since cure is no longer deemed an option) and patients and family members alike are the focus of care. With such support, dealing with situations that are intense and difficult by their very nature is made more achievable.

Palliative Care and the End of Life for the Elderly (Non-disease Death)

Hospice care or palliative care are terms usually associated with end-of-life care when someone is ill. For example, the Victoria Hospice program, which serves close to 800 patients and families each year, will typically have about 84% cancer patients and 16% persons who have ALS, end-stage heart or lung diseases, AIDS etc. Is palliative care, then, appropriate and available for older persons who are dying "of natural causes"? If so, how, where and by whom will this care be provided? If we look at a useful definition some answers may emerge:

Hospice care or palliative care is an interdisciplinary program that provides active and compassionate services to comfort and support individuals and families who are living with dying from an advanced progressive illness or are bereaved.

Palliative care programs have an additional role in care for those other than the dying. One aspect of palliative care is palliation. It is the application of one or more specific interventions to bring about the relief of specific symptoms. Palliation is fundamental to the provision of all health care and therefore palliative care programs have a role in advocating, teaching and supporting effective palliation.

It seems then, that hospice or palliative care programs will not be involved in care at the end of life for elders dying of natural causes. However, as the definition states, hospice and palliative care programs take responsibility for educating other health caregivers about the theory and practice of palliation. This aspect of care at the end of life is essential if quality of life is to be maintained.

When we speak of quality of life we are actually looking at a complex field. Here are some of the factors that influence quality of life for elders, with a comment on how the ideas of hospice or palliative care can make a difference.

When we look at physical and emotional symptoms, we want to help people maintain control over their lives and decision-making power.

When we look at physical and emotional symptoms, we want to be able to manage them so that a person is comfortable in body, mind and spirit.

Care planning allows thoughtful discussion to occur before there is a crisis, and enables people to express their clear wishes about the kind of care they wish to have when they are nearer to death. This will include discussion of where the individual would like to be (home, facility), what their attitude is toward resuscitation (CPR) and what specific kinds of care they wish to have or to avoid. Communicating these ideas with family, physician and others and perhaps formalizing them in a Living Will can make it much more likely that the person will have the care they desire, even if they become unable to make their own decisions at the time. New Guardianship legislation will be proclaimed by British Columbia early in the year 2000 that gives clear status to this kind of effort.

Quality of life also involves the satisfaction of person and family members concerning the care they receive, in whatever setting, and the ability to discuss and question it. For those whose care is primarily provided by the family physician the chance to discuss openly and honestly with the doctor would be a great help. Sometimes this can be accomplished simply by asking for it!

A key factor experienced at the end of life is called family burden. Even though there is no particular illness, the demands of personal care, companionship and support may be difficult when the caregiving spouse, too, is elderly and frail, family members are living elsewhere, and supports are not in place. Planning and accessing what is available through Home Care Nursing, Home Support and other services of the Capital Health Region needs to be coordinated with the family physician and any resource people available.

These factors that so clearly impact a person's quality of life are complex and inter-related. Advice and information is always available from the Victoria Hospice Society and the Family Caregivers' Network Society.

By Jerry Rothstein, Victoria Hospice

Palliative Care and Dementia

What is dementia?

The longer we live, the more likely we are to experience dementia. As life expectancy has increased, so has the incidence of dementia. Dementia is a general term that describes a deterioration of a person's intellectual, emotional and cognitive faculties to the extent that daily function is impaired. Alzheimer's disease, in which nerve cells in the brain die due to plaques and tangles, account for 60% of all dementia cases. Vascular dementia, accounting for 20% of cases is caused by small strokes.

The care of people with dementia falls mainly on family and friends. As dementia reaches the severe stage, the responsibility of caring often becomes too difficult for family and home care services and the person is often admitted to a long-term care facility for the remaining years of life. Current research suggests that only 20% of people with dementia die at home.

Barriers to Palliation in Dementia

Illnesses such as Alzheimer disease are progressive and terminal. While research holds hope, there is no cure at this time. The duration of a dementing illness is 8 to 20 years after diagnosis. Progression may be fast or slow, depending on many factors. Survival time is very difficult to identify and the last stages may be lengthy. Co-existing illnesses may worsen dementia more rapidly. Access to traditional hospice programs is difficult because they are generally focused toward people with 6 months or less to live.

There is still poor public and professional awareness of dementia, its stages and progression and how to get a proper diagnosis. Some families have difficulty with telling the truth about the diagnosis to the person with the disease. While confusion may preclude dialogue, dementia is like any other disease – most of the time people are aware that their mental powers are deteriorating and they have a right to know and speak about what is happening to them.

The Principles of Palliative Care Can Be Applied in Dementia

In reality we do not think about palliative care in the early stages of dementia, but the fact is that providing good palliative care in dementia begins early on with:

- accurate diagnosis and disclosure
- patient and family education and support
- planning for future incapacity by identifying a substitute decision maker who will respect the wishes of the person when they can no longer speak for themselves.

It may be appropriate to withdraw unnecessary medications and treatments as feeding and general handling become more difficult. There are still beliefs that people with dementia do not feel pain but this is not true and pain must be adequately controlled. If other health problems arise it is important to remember that aggressive treatment will not alter the underlying dementia and in fact may worsen it. Decisions about transfer to hospital must be carefully considered. In dementia, it is not uncommon for the person to experience delirium (fluctuating level of consciousness, severe restlessness, agitation) when unwell. In this state, cognition worsens significantly, sleep and behaviour changes and there may be falls and injuries. Delirium must be carefully assessed and sedating medications may have to be used. The focus must be adequate support and symptom management. When the final stage is reached, comfort, dignity and quality of life are the top priorities.

During the dying process, families benefit from participating in the care and receiving support during and after the death. The journey of dementia can be a long road. At the time of death, it is important to remember and celebrate the person's life and contributions, as well as taking time to grieve, in whatever way is appropriate, so that healing and renewal can begin.

By Fiona Sudbury, Clinical Nurse Specialist, Capital Health Region

Palliative Care and Terminal Illness

The previous four articles have thoroughly described what palliative care is, what services are provided by Victoria Hospice Society, palliative care for the elderly and anticipatory grief. This article will discuss some of the common issues that arise for patients with a terminal illness and their families and briefly how we might address them.

First of all it is worth reiterating that not all of the 800 or so patients we care for in a year have a cancer diagnosis. In the early 1980's this indeed was true and in fact, is where we gained much of our expertise in managing difficult symptoms such as pain. At present our statistics reveal that cancer accounts for approximately 85% of our presenting diagnosis while non-cancer diseases such as AIDS, ALS or Lou Gehrig's disease, end stage heart and lung disease make up the remaining 15%.

Pain is one of the symptoms we treat in Hospice Palliative Care. It is said that approximately 2/3 of cancer patients will experience pain at some time in the course of their illness. Our interdisciplinary team has a great deal of experience in addressing not just physical pain but emotional, social and spiritual pain.

Most pain can be easily managed by following a few basic principles such as:

1. taking pain medicine regularly – not just when the pain gets “really bad”
2. assessing the source of pain thoroughly. Pain arises from many varied sources. Other drugs such as anti-inflammatories or non-steroid anti-inflammatories, i.e. ones used to treat arthritis, commonly are powerful relievers of bone pain; and
3. prescribing laxatives along with narcotics. Very important to prevent constipation.

Shortness of breath is another symptom we see frequently and one, which is very frightening for our patients. Thus, it too requires prompt action and often an increase in the opioid (pain) medication is quite helpful to suppress the sensation of shortness of breath. Oxygen therapy, contrary to public opinion, is rarely helpful. Having lost of pillows to elevate the upper trunk and a fan to simply move the air, however, is helpful. Finally I’d just like to touch on the issue of hydration and feeding in general.

When a person is dying, their body systems are slowly closing down. Less physical activity means the person requires fewer calories. Nausea may be present as are feelings of distention in the abdomen – both causing folks to feel less likely to want to eat and drink as they once did. This is normal. It is much harder for loved ones and caregivers to sit by and not try to encourage “just one more bite”. It has been our experience that rarely is an intravenous helpful. Most often it aggravates symptoms such as lung congestion or swollen ankles.

Any inquires about these or other symptoms in the palliative patient can be directed to the client’s Home Care Nurse, Family Physician or Victoria Hospice.

By Fern Anderson, Clinical Nurse Specialist, Victoria Hospice