

A Time to Care

*Caring for someone
seriously ill at home*

Lions Gate Hospital

231 East 15th Street
North Vancouver BC V7L 2L7

Tel: 604-988-3131

Contents

	page
Introduction	4
Who can help you?	5
Preparations before going home.....	10
Personal care	13
Emotional support	19
Looking after yourself	23
When death is close... ..	26
Useful organizations, community services and resources	29
Helpful books	30

Useful phone numbers

If you are caring for someone seriously ill at home, you may wish to write down the names and telephone numbers of persons you might want to contact regularly or in an emergency.

	Phone #
Family doctor (GP)	
Palliative Liaison Nurse	
Community Nursing service	
Local pharmacy	

Introduction

The aim of this booklet is to assist people who want to care for a seriously ill family member or friend at home. It is not unusual for those who are very ill to want to be cared for in their own homes. The Palliative Program recognizes the need to help such people and aims to achieve it through its patient care services and by assisting families in these circumstances.

Often family members and friends can find it a very rewarding experience. You may also find that caring for someone in this way can help strengthen relationships.

Making the decision to care for a seriously ill relative or friend at home is not easy. At first you may feel overwhelmed or nervous at the amount of care they will need. Or you may feel that you don't have enough physical or emotional strength to deal with it all. Even so, you may still wish to make your relative or friend as comfortable as possible in familiar surroundings. With the right help and support it can be done.

Depending on how sick the person is, it may involve 24-hour care and be too much for one person to take on. For that reason getting help from others and sharing the work is important.

Before your relative or friend is discharged from hospital, planning and preparation is needed to make the change from hospital to home as easy as possible.

This booklet talks about the practical aspects of caring for someone who is seriously ill. It explains how to give the care that is needed. It also helps to make you aware of the resources in the community that are available to you as a care giver. Contact numbers and details of local services are given at the back of the booklet as well.

As a caregiver it is very important to look after yourself and be aware of your own needs and emotions. Be open to all offers of help and get as much support as you can during this time.

Who can help you?

If you decide to care for your relative or friend at home, there are many healthcare professionals who can give you practical help and support.

Some work in the community and some are attached to hospitals or hospices, while others work between the hospital and your home.

Depending on where you live, services can vary from one Health Service Delivery area to another.

You may hear the words 'palliative care' mentioned. This refers to treatment and care that is given to someone who is seriously ill in order to relieve symptoms. The treatment will not cure them but will give them the best quality of remaining life. Your GP or community nurse can tell you what palliative care services are available locally.

The following is a list of healthcare professionals who will help you give the best possible care to your loved one. It does not matter if your relative or friend is based at home, in a residential care facility, general hospital or hospice. Usually these professionals work as part of a team in the care of your relative or friend.

General Practitioner

Your family doctor or general practitioner (GP) is an important part of the team that will take care of your relative or friend. The GP is medically responsible for their care at home. He/she works with the community nurse and others involved in the care of your relative or friend.

Community Nurse (CN)

The Community Nurses are Registered Nurses and work with the GP and other professionals in the community.

The CN will make an assessment of your relative or friend as soon as they are informed by the hospital or GP.

After their assessment, the CN will discuss what other services your friend or relative needs. They may ask other professionals or services to be involved in their care. That way you do not have to worry about contacting lots of people yourself. These services can include those of an occupational therapist (OT), speech therapist or physiotherapist (PT).

The Occupational Therapist or Physiotherapist will discuss what kind of equipment can help to make your relative or friend more comfortable or indeed anything that can help to improve their quality of life. They will guide you on how this equipment can be obtained. Very often the equipment required can be provided free of charge through the Palliative Benefits Program.

Home Care

Other healthcare staff may be available to come to your home and help with washing and dressing your relative or friend. The Community Nurse will let you know if this service is available to you.

Specialist Palliative Care Service

The specialist palliative care service is also known as the Palliative Outreach Team. This team gives advice and support to patients and families in the community.

They are specially trained in managing pain and other symptoms and helping you cope with any emotional distress. The team is made up of doctors, nurses and other healthcare professionals. It may include a social worker, patient and family support counsellors and pastoral care.

Depending on the area in which you live, specialist palliative care teams may have more healthcare professionals available. The development of these services is ongoing.

Palliative Liaison Nurse (PLN)

Your relative or friend will be referred to the Palliative Care Program by his or her GP or hospital physician. Once they are referred, the Liaison Nurse (PLN) will arrange a visit. The PLN will work with your relative or friend to see how best to help him/her cope with their illness. But they will also work with you and your family. They will explain who else is on the team and how they will be able to help you and your relative or friend.

The Palliative Care Program does not necessarily take over the care of your relative or friend but works very closely with their GP, Community nurse and any other healthcare professional or service already involved in their care.

Palliative Home Care Clinician

The Palliative Home Care Clinician is a member of the palliative care team and works in the community and liaises closely with the hospital team. When visiting you at home, he/she will work closely with the GP and Community Nurse to give support to your relative or friend. These nurses can also visit patients in hospital or in residential care facilities.

Palliative Care Service in the General Hospital

A palliative care service is available in most general hospitals.

This service works with the hospital team to give advice and support. A referral to the palliative care team in the hospital is made by the hospital physician or GP.

Palliative Care inpatient unit

A palliative care inpatient unit may be available in your area.

Hospice

Admission to hospice may be suggested by the doctor in charge of your relative's or friend's care. You can discuss this in more detail with your palliative care team.

Palliative Day Centre

A Palliative Day Care/ Day Hospice may be available in your area. Your Palliative Liaison Nurse can give you more information about this service.

Community Pharmacist

Your community pharmacist will make sure that all the medication ordered on the doctor's prescription, or bought over the counter, is correctly and safely supplied to you. They will also make sure that any new treatment prescribed for your relative or friend is safe to take with other medications.

They can also give information and advice on how and when the medications should be taken and on any common side-effects to expect.

If you need more supplies, they can arrange this for you too. If there are any problems, they can discuss them with your GP and other healthcare professionals.

Physiotherapist

The physiotherapist can help your relative or friend with any mobility problems. They can also help with symptoms such as pain or excess fluid in the tissues or lungs. At home, they can teach you or family members how to move someone gently and position them in bed or in a chair. This is important because it will reduce pressure on sensitive areas.

Occupational Therapist

The Occupational Therapist can make suggestions about any equipment or home adjustments that can make your relative or friend more comfortable. They can also help to make your relative or friend as independent as possible. This is done by making sure they can do everyday tasks like bathing and dressing, eating and drinking, working (if possible) and able to enjoy any leisure activities.

Palliative Social Worker

If you are finding it hard to cope with caring for your relative or friend at home, the Social Worker can also offer emotional support and help. He/she can also help children to cope with having a sick person in the home.

Caring for a relative or friend at home can be difficult, especially where finances are concerned. Your relative or friend may have been the main breadwinner before becoming ill, or you may have decided to give up your own job and work part-time. As a result, money may be tight, especially if you have extra expenses such as heating, laundry, special equipment or special diets.

The Social Worker can tell you about financial supports and community services. Some benefits are means tested but not all. The Social Worker works at the Hospital.

Volunteers / Support Groups

There are a number of voluntary organizations that may provide help and support for you as a caregiver and your relative or friend.

In your situation they can offer a variety of practical support and give advice. Your Community Nurse or Palliative Liaison Nurse can inform you of local groups.

He/she can also help children to cope with having a sick person in the home.

Preparations Before Going Home

Once you decide to care for a seriously ill relative or friend in their home, it is important that you understand exactly what is involved.

Being a caregiver may mean helping your relative or friend with mobility, bathing and dressing, going to the toilet, giving meals and giving medication. It is important that you make sure to ask the nurses for advice with any of these tasks.

Before the person you are taking care of is discharged from hospital, sit down with the hospital staff and plan what you need in advance.

Involve your relative or friend, if possible, because they should have a say in the matter as well. This means finding out information about:

- Medication – how often they must be taken
- Diet – any special food or drink that must be taken
- Mobility – advice about lifting or moving
- Practical arrangements – location of the bedroom and bathroom
- Aids and equipment – special beds, mattresses
- Nursing services available to you at home – the Community nurse.

The hospital team will contact your GP and Community Nurse to involve them in your relative's or friend's discharge from hospital. The team will update them on their condition and the care that will be needed. However, it would be helpful for you to make contact with both your GP and Community Nurse too before your relative or friend comes home.

Medication

Ask for prescriptions at the time of discharge.

Do ask one of the nurses on the ward to go through the prescription with you so that you have a good understanding of the medication before going home.

Practical arrangements

Bathroom

One important thing to consider is access to the bathroom.

- Is the bedroom too far from the bathroom?
- Does getting there involve great effort on the part of your relative or friend?
- Are they likely to wet or soil themselves on the way?
- Do they have access to a commode or urinal?

If your relative or friend is incontinent, you will need to discuss this with the nurse before discharge from hospital

Stairs and bed

Are there stairs in the house? Will your relative or friend be able to manage the stairs? If not, discuss this with your relative or friend as a bed downstairs may need to be considered. If possible, make room around the bed so that there is easy access to help them when moving position or getting in and out of bed.

If your relative or friend is upstairs, a baby alarm may be useful in the room, particularly at night. This can monitor them when you are downstairs or in another room. If you don't have access to a baby alarm, a bell can be useful so they can call you if needed.

Sharing responsibility

If you have a large family, it can be useful to plan a roster so that everyone is not there at the same time. That way everyone gets rest time and everyone is included in caring for your relative or friend.

Aids and equipment

Various items of equipment may be available to help you care for your relative or friend at home. The Occupational Therapist will be able to advise you on what equipment is available, how to get it and how to use it.

Beds

It is important that your relative or friend is comfortable in bed. A lot of time may be spent in bed, even if they are not fully bed-bound. The Occupational Therapist will help arrange the most suitable bed and mattress for your relative or friend. Also, the Community Nurse will give advice on the best way to make them comfortable in bed. It also helps to have a good supply of pillows at home.

Commodes, bedpans and urinals

If your relative or friend has difficulty getting to the toilet they may need a commode, bedpan or urinal. The Community Nurse or Occupational Therapist will be able to arrange getting a commode for you. It is also possible to buy a urinal at the local pharmacy.

Wheelchairs and walking aids

Depending on their condition, your relative or friend may have difficulty walking. If so, the Physiotherapist will be able to arrange a wheelchair or a suitable walking frame.

Personal care

Washing

Washing your relative or friend regularly is important for many reasons.

Not only is it good for their personal hygiene and comfort but also for their morale. It is also a good way to check for early signs of skin redness and prevent infection. For those with an advanced illness it often takes longer for bruises, infections or wounds to heal.

Many people who are in bed for long periods may sweat, get sticky and become uncomfortable. If your relative or friend cannot get out of bed or wash themselves, they will need to be given a bed bath. Discuss this with your Community Nurse, who will offer advice and support. It may be possible to arrange for someone to come in each day to do it.

When you wash your relative or friend:

- Be as gentle as you can.
- Rinse the soap off fully and dry the skin gently but thoroughly. Change the water in the bowl several times during the wash. Avoid the use of powder or strongly scented soaps as this may cause dryness and irritation
- Keep your relative or friend covered as you wash each part of their body. Only expose the parts that you are washing. This helps to keep your relative or friend warm but also maintains their dignity.
- Look for dry or red skin areas, particularly on the ears, back of the head, shoulder blades, elbows, spine, hips, heels and soles of the feet. Use a mild moisturiser on these areas.
- Use an electric razor when shaving as it may be easier.

Moisturizing and massage

It can be very soothing for your relative or friend to have limbs gently massaged with a light moisturizing cream. Discuss with a member of the team caring for your relative or friend what are the most suitable creams or products. You may also need advice on caring for any areas of the body that have been treated with radiotherapy.

Mouth care

Clean your relative's or friend's mouth or dentures gently every day or more often if needed. If their mouth is too sore to use an ordinary toothpaste and toothbrush, use a fine baby toothbrush instead. It is best to avoid mouthwashes or lemon and glycerol swabs as they can dry out the mouth even more and can cause stinging.

Grapefruit juice or pineapple juice has been proven to be very effective in keeping a patient's mouth clean and has a much kinder flavour.

You may find that your relative or friend develops thrush or mouth ulcers. These are very common when someone is very ill. Thrush looks like white patches or spots on the tongue, gum or inside the cheek. It is best to clean dentures in the normal way. Often when a person is very ill, their dentures can become loose and cause mouth ulcers. If the mouth or tongue becomes very sore or coated, tell the Community Nurse or GP, who can give you advice on what to do. If the lips are dry, Vaseline® or a flavoured lip balm can be used to moisten them.

Hair washing and grooming

Being in bed all the time may make it hard for your relative or friend to feel or look well. Washing their hair may make them feel much better.

Often this may not be easy to do, if they are confined to bed. Discuss with the Community Nurse how best to do this.

Encouraging women to apply some make-up can boost morale too. Also, encouraging men to shave with an electric or hand razor can keep their spirits up. If your relative or friend is unable to do this by themselves, talk to the Community Nurse

Nail care

If your relative's or friend's nails need to be trimmed, discuss this with the Community Nurse. However, simple painting or manicure can lift the spirits.

Mobility

It is important that your relative or friend does not stay in the same position all the time. Encourage and help them to move and change their position, if possible. This will boost not only their physical comfort but also their morale. It is important to help them feel independent for as long as possible.

Make sure that the floor is cleared of all obstacles such as shoes, rugs or other items that may trip them up. If they need to use a commode or sit out on a chair, make sure it is placed close by or as near as possible to the bed.

If you are looking after someone who needs help getting in and out of the bed, you will need guidance on how to move and lift them safely.

When moving someone, be as gentle and careful as you can. It is very important that you first discuss with your Community Nurse the correct way to lift and move someone. You do not want to cause injury to yourself or to your relative or friend.

Pressure sores

When your relative or friend is confined to bed or sitting in a chair for long periods they can become sore and numb at certain pressure points.

Any bony part of the body can become sore if pressure on it is not relieved frequently. People who are very ill and very thin are most at risk of developing sores. These can be uncomfortable and can increase the risk of infection.

In the long run it is better to prevent pressure sores from developing at all. Discuss with your visiting nurse the most suitable way to relieve pressure. It can be done by using a special mattress or cushion and these may be available from the Benefits Program at no cost to you or the patient. If you notice any change in the texture of their skin, such as redness or blistering, tell the nurse.

Poor appetite

Often people who are very ill have a poor appetite or none at all or may feel nauseous. Sometimes they may have little or no energy to eat, have a sore or dry mouth or find swallowing difficult.

The visiting nurse or the GP may be able to offer advice.

- Give small meals often to your relative or friend instead of set times of the day. Or give meals whenever they feel like eating.
- Make sure the food looks as attractive as possible. Small meals and snacks can also help to stop your relative or friend feeling sick.
- Try moist food as it is often easier to take. It will help to prevent a dry mouth too.
- Offer meals when your relative or friend is sitting upright in bed or in a chair, if possible.
- Give small meals often to your relative or friend instead of set times of the day. Or give meals whenever they feel like eating.
- Make sure the food looks as attractive as possible. Small meals and snacks can also help to stop your relative or friend feeling sick.
- Try moist food as it is often easier to take. It will help to prevent a dry mouth too.
- Offer meals when your relative or friend is sitting upright in bed or in a chair, if possible.
- If they have difficulty taking solid food, try liquidised food or a nourishing drink instead. You can also discuss with the visiting nurse the range of nourishing drinks now available.
- Give them a glass of crushed ice or a bowl of ice cream as it can be refreshing. It will help to keep their mouth moist too.
- Use a straw for drinking as it may help if the mouth or tongue is sore.
- Consider using a baby's feeder cup as it can sometimes be an effort to sit up to drink.
- Don't feel upset if they eat very little of your carefully prepared meal.
- Talk to the visiting nurse if your relative or friend is unable to take any food. Nausea or vomiting may prevent them from eating and drinking.

Toilet needs

It can be embarrassing having to talk about this subject with your relative or friend. In fact, it can be one of the most difficult aspects of caring. Even so, do talk to your visiting nurse if you would like more advice on this matter.

There are many things that can affect how often urine is passed and the bowels are opened. These can be changes in eating habits, loss of appetite, lack of mobility and some medication. Discuss with the visiting nurse any difficulties you are experiencing. It is important that you ask for advice early. If the person you are caring for has no problems eating, it is helpful to encourage extra drinks. You can also add more fruit and high fibre foods to their diet.

Incontinence

At some stage of their illness, your relative or friend may lose some or all control of their bladder or bowels. If this happens, ask the visiting nurse for advice on incontinence. It may be possible to reduce the problem by making sure the bedroom is not far from the toilet or keeping a commode or urinal near the bed at all times.

The visiting nurse can give you information about using incontinence wear and protective measures for the bed. This is to make sure that your relative or friend is dry and comfortable and the bed is clean. If this does not work out, the nurse may suggest a catheter. This is a tube placed in the bladder so that the urine can be drained away into a special bag.

Having a catheter is painless and bags and tubes can easily be hidden by bedclothes. For men it is also possible to drain urine using a tube connected to a sheath that fits over the penis.

Incontinence and using commodes in the bedroom can also cause concerns over strong smells. There are many ways of dealing with this so do talk to the visiting nurse about it.

Sleep problems

Your relative or friend may find it hard to sleep at night. This can be due to pain, sleeping a lot during the day or being anxious and finding it hard to relax.

There are many ways to help them relax and fall asleep at night. For example, listening to music, reading, meditating or a warm drink in the late evening may help. Make sure the bedroom is quiet and not too hot or cold either. Discuss ongoing sleep problems with your GP or visiting nurse.

Pain or any distressing symptoms

If your relative or friend experiences pain or distressing symptoms please encourage them to discuss it with the visiting nurse or a member of the specialist palliative care team. It is important that your relative or friend takes their painkillers regularly or as prescribed. If their pain gets worse, talk to the GP or visiting nurse.

Gentle massage is also a good way to relieve pain. It may be helpful to keep a record of when they are in pain, how long it lasted and what helped to relieve it or not.

Emotional support

It is natural for people with cancer or a serious illness to feel sad, anxious or depressed at times. Indeed they may experience a range of emotions and sometimes get cross or irritable with you. It is possible too for your relative's or friend's feelings to change from day to day or even hour to hour. Remember their emotional well-being is just as important as their physical health.

Some ways to help deal with their emotions and feelings can include listening and talking, touch or simply being with them.

When to listen and when to talk

When faced with the prospect of the death of a family member or friend, it brings a strange mixture of feelings. It can be hard to know what to say to your relative or friend because the future is so uncertain.

You may be afraid of saying the wrong thing and want to protect them and keep them free from worry. As a result you might pretend that everything is fine and carry on as normal.

People with a serious illness can sometimes become anxious and depressed. However, it can be hard to tell if their symptoms are part of their illness or part of their anxiety or depression. They may lose interest in their surroundings, lose their appetite, be angry, irritable and cry, or have problems sleeping.

If you feel concerned about low mood discuss it with the visiting nurse or the GP.

- Listen carefully to what your relative or friend is saying and respond to it. You may not think you are doing much by just listening. But in fact it is one of the best ways to help.

By listening carefully you allow them to share their feelings which can help you to understand their concerns better.

They may speak about 'tying up loose ends' or may be worried about finances such as wills, mortgages or insurance. Also, they may want to speak to family and friends to make amends or just to catch up.

- Don't make your relative or friend feel lonely and isolated by not talking to them or brushing off what they say lightly.

cont...

They may not want reassurance but just to be listened to as they talk about their fears and hopes. Even when there is no hope of recovery, they may just want to know that they will not be abandoned and alone.

- Be as honest as you can and be prepared to face the truth if that is what your relative or friend wants.

Often people who are dying do not want to focus on what is going to happen to them. But at the same time they want those around them to be honest.

Sometimes they may speak about dying, state they are going to die or ask awkward questions such as 'Am I going to die?' or 'Am I dying?' In this situation it is very hard to say an outright 'yes' to such questions. In fact it is never easy to talk about death. You may find it easier to respond by asking them a question instead. For example, 'Why did you ask that?' or 'Do you think you are dying?'

This can give them an opportunity to express their worries.

- Sometimes your relative or friend may not want to talk. They just may not feel the need. Respect this view. Just knowing that you are always ready to listen to them should reassure them.

Sometimes they may just want to sit in silence with you for company.

Touch

Communicating with someone who is seriously ill does not always need to be verbal. As their condition becomes worse and their strength weaker, your friend or relative may speak less and less or you may find it increasingly difficult to understand what they are saying.

You may also find it hard to express your own thoughts and feelings to them. At this time, touch can be good way to express your love and appreciation. By giving them a hug or holding their hand or by gentle stroking or massaging, it can help them to relax. Sometimes it may even relieve pain and sleeplessness. The fact that they can sense your presence too can also bring them great comfort and peace.

Peaceful environment

It helps to have a peaceful and soothing environment for your relative or friend when they are seriously ill and getting weaker. Music can be especially helpful and playing their favourite CDs or tapes can be very calming. If your relative or friend has pets, such as a cat or a dog, there is no need to exclude them from the room. A calm atmosphere should be encouraged and avoid crowding the room with family members and visitors. A room that has fresh or circulating air is also better than a hot stuffy one.

If your relative or friend has used complementary therapies in the past or is thinking about using them, talk to your visiting nurse or GP about how appropriate it is at this stage.

Spiritual care

When faced with a serious illness, your relative or friend may start thinking about the meaning and purpose of life, of God and the afterlife. They may have ‘unfinished business’ like spiritual or religious needs they did not get a chance to deal with during their lives. As a result, they may now want to put their ‘house in order’.

In times of stress and sadness many people find that their religious faith can be a great comfort to them. Your relative or friend may ask to speak to a local priest, minister or religious leader for spiritual support. The illness of your loved one may even affect your own spiritual well-being. You too may wish to make contact with a religious leader.

Looking after yourself

Taking care of someone with a terminal illness can be both a challenging and a rewarding experience. It can bring great personal satisfaction, but it can also be tiring, frustrating, distressing and isolating at times.

Indeed you may become a caregiver overnight and feel that you are not experienced to handle the care of your relative or friend. And because their illness is unpredictable, you may be fearful or anxious about the future.

Caring for a loved one may result in you wanting to be at home all the time in case something happens. You may feel guilty or be reluctant taking a break. Or depending on the support you are getting from others, you may have few opportunities to relax and take a break.

Indeed you may feel angry or come to resent your relative or friend for the changes their illness has brought to your lifestyle.

However, it is important that you look after your own health too so that caring does not result in you getting stressed or sick.

Make time for a break each day: a walk to the shops, a trip to the hairdresser/barber, the library or cinema, or the odd evening out with friends. Give yourself little treats at home: read a favourite magazine or newspaper, sit down for a leisurely cup of tea or coffee, or have a relaxing soak in the bath.

If you have any of your own health concerns don't put them off but see your doctor sooner rather than later.

It may help to think about the following questions and, even if the answers are no, they can help you to focus on your needs too.

- Do I know someone who is a good listener?
- Can I trust them when talking about my feelings?
- Do I get enough rest and sleep?
- Do I eat regular meals and a healthy diet?
- Do I get some regular exercise?
- Have I got regular times for relaxation?
- Am I allowing others to provide care and help too?

Family and friends

Remember to ask family and friends for help when you need it. Take up all offers of help, especially with finances, cooking, housework, shopping, or even company for yourself. Don't get weighed down by all your relative's or friend's needs. There are many healthcare professionals to help you if you find it hard to cope.

Talking to children

When caring for a relative or friend and there are young children involved, they may have many questions for you. In this situation it is best to obtain professional advice. In many areas there are Patient and Family Support teams or Counselling services available that have special programs for children. Ask your Palliative Care Team.

How much you tell children about the illness will depend on how old they are. Very young children don't understand illness and need a simple account as to why their parent or friend has to go to hospital or why he or she is ill at home and needs taking care of. Slightly older children will need to be told more.

An open honest approach is usually the best way for all children. Even very young children can sense when something is wrong. So don't keep them in the dark – reassure them and talk to them in their own language.

Practical matters

By knowing the wishes of your relative or friend, it can make dealing with a number of practical matters easier. To lessen any stress for you and your family when your relative or friend has died, it is a good idea to prepare a little beforehand.

It does help to think about some practical issues that can affect your future.

It is best to encourage your relative or friend to make a will, if they have not done so. Or at least provide an opportunity to talk about it. Inheritance problems can often arise when no will is made.

It is also useful to know where important documents belonging to your relative or friend are located. This can include such things as the deeds of their house; their will; passport; driving licence; birth, marriage or divorce certificates (where applicable); details of bank or building society accounts; insurance and pension policies.

When death is close...

When death approaches it is natural for it to be a sad and stressful time.

Dying at home may seem like the most peaceful, safest place but in practice this is not always possible for many reasons. Your GP or visiting nurse can offer advice and guidance in deciding the best place of care for your relative or friend at this time.

How do I know if my relative or friend is dying?

If you are caring for your relative or friend for some time, you may notice a change in their condition. The visiting nurse or GP will be able to answer any questions you have about this change and will advise you about any signs that your relative or friend is dying.

As the time draws near, their appetite will reduce or they may have difficulty swallowing. Offer small servings of a favourite food or drink but without forcing them. Do not worry if your relative or friend stops eating and drinking altogether.

Your relative or friend may sleep more and sometimes be drowsy or difficult to wake. So it is best to plan conversation times for when they are more alert. They may also have difficulty seeing and may develop a fixed stare. In this case, it can help to leave a dim light on in the room.

Sometimes they can become restless or confused. For example, they can pull at the bed linen and become confused about the time or may not recognise familiar faces. It is best to speak calmly so as not to frighten them. Remind them of the day, the time and who is in the room. It can be a comfort to them for you to hold their hand, even if they cannot respond.

When someone is drowsy or unresponsive don't assume that they cannot hear you. They may be aware of people close to them and recognise familiar voices. For this reason it is important not to discuss their illness or changing condition in their presence.

As your relative or friend becomes weaker, their breathing may change and become irregular. When breathing becomes shallower, secretions can build up at the back of the throat. These may sound noisy like a rattle. But it does not mean that your relative or friend is uncomfortable.

Time of death

It is very hard to predict when death will occur. If it looks like it's about to happen you may want to have someone with you. Continue to sit by your relative or friend and you will notice when they are no longer breathing.

When death occurs, you may wish to sit with your relative or friend for a while afterwards. Naturally you will have many emotions and feelings at this time. You may feel shocked or it may all seem unreal.

When a death at home is expected it is not necessary to call 911. In your own time, call your GP so that the death can be certified. Call the undertaker when you feel ready. They will help and guide you with all the aftercare of your relative or friend and the funeral arrangements.

Bereavement

When someone close to you has died, there is a natural period of sadness and loss. You are likely to experience a range of emotions from shock, relief, guilt to grief for a long time afterwards. These are all normal reactions. Indeed some days you may feel better than other days.

It is best not to try to do too much too soon. You will need time to get used to the loss of your relative or friend and adjust to a new routine.

Don't make any quick decisions about changes to your life, e.g. moving house, as you may regret them later on. Wait until your grief is less strong.

There are many organisations available to help you at this sad time. If you have concerns or find it hard to cope, contact your GP or your Palliative Care Program.

Useful organizations, community services and resources

Family Services of the North Shore
familyservices.bc.ca

Lions Gate Hospice Society
www.lionsgatehospicesociety.org

Handy Dart Transport
www.transitbc.com

Meals on Wheels
www.northvancouver.com/community/organizations
www.nscr.bc.ca/information/caregiver

The following can be found online at <http://vch.eduhealth.ca/>

Palliative Care Program Information Booklets

North Shore Palliative and Support Care Program
(GV.110.P351)

Helping Children and Teens During a Difficult Time
(GK.770.H45)

Guidebook to Help Us During Difficult Times (GV.100.G85)

North Shore Palliative Care Day Program (GV.110.P35)

After the Death of a Loved One (GV.300.D349)

Grief & Loss Series:

Adolescent Grief (GV.200.A77)

Adults Grieving the Death of a Parent
(GV.257.A39)

Coping with Christmas and other Special Dates
(GV.250.C67)

Coping with the Death of your Same Sex Partner
(GV.250.C672)

Grieving the Death of Someone Close (GV.250.G75)

Living Through the Death of your Partner or Spouse
(GV.250.L59)

Talking to Children About Death (GV.250.T35)

Ten Things to Know About Grief (GV.200.22.T46)

The Grieving Family (GV.200.G75)

Understanding Grief (GV.200.U53)

When Someone You Care About is Grieving (GV.200.W43)

Helpful books

What Dying People Want, David Kuhl

Final Gifts, Callan

At Home with Dying, Collett Merrill

Dying Well, Byock, Ira

Would you like to help us?

Much of our Palliative Service is supported by LGH Foundation and generous donations from our community.

If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us.

LGH Foundation

For more copies, go online at <http://vch.eduhealth.ca> or
email pchem@vch.ca and quote Catalogue No. **EF.100.T56**
© Vancouver Coastal Health, June 2016

The information in this document is intended solely for the
person to whom it was given by the health care team.
www.vch.ca