



QUEEN VICTORIA CARE

EST. 1891



PALLIATIVE CARE

INFORMATION
BOOKLET

INTRODUCTION

This booklet is intended as a guide for families and friends. It is not exhaustive, but it is hoped that the information will help families to understand and assist with the care of their loved ones, especially when they are dying.

HOW TO HAVE THAT DIFFICULT TALK ABOUT DEATH AND DYING

Why is it difficult to talk to our older family members?

Having a conversation with the people you love should not be difficult.

Think of it as attending to your loved ones' wishes and knowing that things will be done their way.

ADVANCED CARE PLANNING



It is very important to discuss the Advanced Care Plan or goals of care, including what medical treatment your loved one wants at the end of their life and where they would like to be cared for. This can also lead into other conversations about who they would like to be present when they are dying, what music they like, who they may want as a funeral director. The list goes on, but we will support you as you go. Having this kind of conversation early will ensure that everyone feels they are able to be part of the discussion.

Talking about death early or before you need to can help you and your loved ones share any concerns, fear and wishes connected with dying. It can ensure that your loved one is able to make decisions on what happens to them in their last days. It may also include how their will and finances are settled, they might like to tell you about organ donation, cremation, or burial, as well as what kind of send-off they would like.



DYING IS A NATURAL PART OF LIFE



WE CALL IT THE CIRCLE OF LIFE

LET'S START THE TALK

There are no right or wrong ways - the conversation will be different for all of us. We just need to start.

When you come to us you will know what questions you would like to ask the staff, don't be afraid to ask.

THIS BOOKLET IS INTENDED AS A GUIDE FOR FAMILIES TO UNDERSTAND AND ASSIST WITH THE CARE OF THEIR LOVED ONES ESPECIALLY WHEN THEY ARE DYING



You may worry that your loved one would not like to talk about death and dying, but that is not always the case.

When talking about death, we can become anxious about what we will hear and worry that we may not be able to emotionally handle the conversation about fears and feelings. This can feel very daunting.

Your loved one may talk about death and dying with staff and their peers at the home more freely and easily than they do with their family, they may be worried about causing you to feel upset or uncomfortable. It is good for them to know that you are open to conversations about death and dying.

Aged care staff often hear from people who have had an experience of a loved one's death, saying that they wish that they had been more prepared for it by having asking questions and having conversations around what to expect when someone dies.

FAMILY

It is important that younger children and grandchildren are included in this discussion as they often have a special relationship with their grandparent or older relative and will want to be part of this. It is important for children to be allowed the opportunity to say goodbye to people who are important to them.



DETERIORATION

This is when a person is declining in their state of health. Signs could be:

- They become bedbound (reluctant or unable to physically get out of bed)
- Spending more time sleeping (lethargic)
- Reluctant with the intake of food
- Difficulty with swallowing
- Fluctuations in consciousness

Recognising that your loved one is deteriorating is important. Care can then be reviewed with the family, nursing staff and the GP. This means we can:

- Start a Palliative Care Plan pathway.
- Ensure symptoms are managed correctly.
- Provide emotional and practical support to the resident and their family.

Care staff spend a lot of time with your loved one and they usually notice when signs of deterioration appear and will let nursing staff know.

PAIN

Pain can be the most worrying aspect of dying.

There are many approaches that can be taken to ensure your loved one is comfortable, such as medication, massage, hot packs, music, or therapeutic touch.

You may like to be involved in this, such as giving your loved one a hand/foot massage.

You can always inform the staff if you are concerned about pain and speak with the doctor or nursing staff about pain relief.

People can worry that taking pain medications in palliative care will lead to addiction. Keeping people comfortable often requires increased doses of pain medications. This is a result of tolerance to medication as the body adjusts, not addiction.

Staff will always be monitoring for pain and discomfort and will work to ensure your loved one is as pain free as possible. Doctors, nurses, and care staff will talk to you and your loved one to find out what is the best approach.



RESTLESSNESS

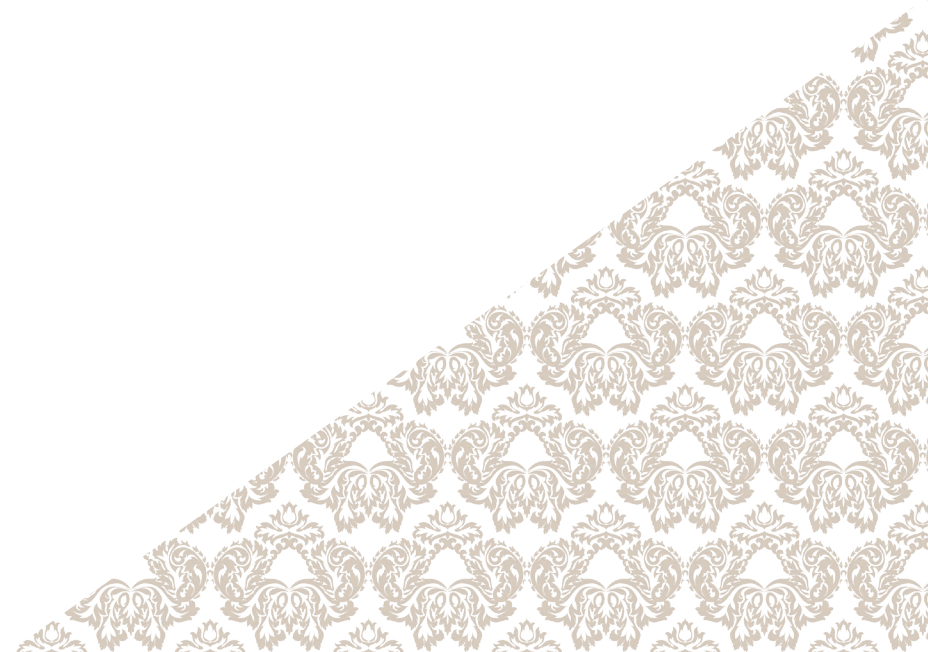
Due to the decreased circulation of blood to the brain and to other parts of the body, your loved one may become restless or agitated.

To help settle them it is comforting for them to hear your voice, lightly massage their head or hands as this can be relaxing. Playing soft music or their favored songs can also be relaxing for them. You can upload some of your loved one's favourite music to our iPad - please let staff know and we can assist with this.

Let a staff member know if you are worried that they are unsettled. Their doctor may order some medication to assist with restlessness and agitation.

PRESSURE CARE

For the comfort of your loved one, staff will do 2nd hourly pressure care just to prevent a pressure area developing on their skin, which would be more uncomfortable for them. They will make slight adjustments, using pillows to support them. Your loved one may be provided with an air mattress to do this automatically.



FOOD AND FLUIDS

It is normal for people nearing death to have a decrease in appetite and thirst, wanting little or no food or fluid. This is because the body will begin to conserve energy.

When a person wants little or no fluid or food, good mouth care and keeping mouth and lips moist will be enough to keep them comfortable.

People who stop eating die of their illness, not starvation.



MOUTH CARE

Residents who suffer from a dry mouth may also experience dry lips, sore soft tissue, bad breath an alteration in taste and difficulty speaking.

There are many ways to alleviate this, and staff will help show you the procedures that we follow at QVC

Some of the things we may use are:

- Ice chips
- Thickened drinks
- Mouth spray that can be sprayed in the mouth or onto the tongue when they have dry mouth.
- Mouth swabs soaked in water or lemonade.
- Paw-paw ointment for dry lips.

Mouth care is more than just cleaning teeth, Mouth care in end-of-life care maintains comfort, self-esteem, and dignity.



TOUCH

Some people like to be touched and sometimes others just don't.

You will know your loved one's preference as they will let you know by movement or just telling you.

But don't be afraid to hold their hand.

Touch and gentle massage can help with pain and agitation.

TEMPERATURE

The bodies temperature may change.

Sometimes the hands, feet and legs may feel cold and other times they may feel hot and clammy

Sometimes parts of their body may be blotchy and darker in colour. This is due to the circulation of the blood slowing down and is a normal part of the dying process. Too many bed clothes may make them hot and restless. We will provide your loved one with comfortable and breathable bedding during their end-of-life care.

BREATHING

Regular breathing patterns may change. Sometimes the breathing may be fast and sometimes there could be long gaps between breaths. Breathing may be shallow or noisy.

This is a normal part of the dying process and is not painful or distressing for your loved one.

GURGLING

An audible gurgling in the throat is a symptom that can appear distressing. This is caused by secretions that build up and cannot be swallowed.

It is possible to give medications that will dry up the secretions and these can be ordered by the doctor. However, this symptom rarely causes discomfort to the person who is dying and is more distressing to those who are standing by.

INCONTINENCE

The amount of urine that a body is producing decreases due to the amount of fluid they are drinking.

Staff will supply a continence aid to ensure comfort, this will be checked and changed at regular intervals.

END OF LIFE CARE

Your loved one who is dying needs care in these main areas:

- Mental and emotional needs
- Spiritual needs
- Physiological needs

Providing physical comfort for

- Pain
- Breathing problems
- Temperature
- Fatigue

If your loved one can still communicate, ask them what they need, if they would like you to massage their hands or perhaps play music at a low volume, this may help to relax them.

When visiting them talk to them or read to them, being present is the greatest gift you can give them.

YOU WILL KNOW THEY HAVE PASSED AWAY WHEN:

They are no longer breathing.

No heartbeat or pulse can be felt.

Eye lids may be half open.

Their mouth may be open.

Pupils are fixed.

A GP or Registered Nurse will conduct a thorough assessment to check for these signs.

None of us can predict accurately, exactly when someone will die. Dying people often set their own time and circumstances and will often die after a specific event (for example, someone flying from interstate) or alone, when things are quiet. Dying people have a deep sense of “knowing” and the time of death is always the “right” time for them.

VISITORS



At the end of life, people usually relate only to a small circle of people and will probably feel most supported by one or two close people who are able to visit regularly.

At this stage, the spiritual dimension of the person is the most important and this is intensely personal and internal. The person will often lose interest in items of news or even in close family matters.

FACILITIES FOR RELATIVES

You are welcome to stay for as long as you like. If you wish to stay overnight, accommodation can be arranged for you.

Meals may be ordered from the kitchen and morning and afternoon drinks will be available for you from the tea trolley. Tea and coffee making facilities are also available.

It is important for you to rest and look after yourself during this time. It may not be easy or convenient for you to always be present. Talk to the staff about where you will be and if you would like to be contacted at any time of day/night in case there is a rapid deterioration or if your loved one passes.

PASTORAL CARE & BEREAVEMENT SUPPORT

Pastoral carers are here in the home on Tuesday and Thursday and can be called any time. Priests or ministers can be called when requested.

There are many resources available for grief and bereavement support. For further information, please ask staff.

FUNERAL HOMES

Ideally a funeral home will be chosen when advanced care planning is first discussed.

Nursing staff will contact the funeral home for you, and they will arrange to collect your loved one, when you are ready.

USE OF THE QVC CHAPEL

We are happy to hold funerals or memorial services in our Chapel. Several Funeral Directors are familiar with the arrangements and will assist you. Please see a senior staff member to book the Chapel and our Catering Services Manager will provide a quote for refreshments.

We thank you for allowing us to share this time with you and your loved one.

If you need someone to talk to please let us know.

With love.

The Staff of the Queen Victoria Home.

Prepared by the Palliative Care Work Team Queen Victoria Home





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*Partnering with people
to live their best life.*